DOCUMENT RESUME

ED 427 476 EC 307 047

AUTHOR	Attawell, Kathy, Comp.
TITLE	Caring with Confidence: Practical Information for Health Workers Who Prevent and Treat HIV Infection in Children. AHRTAG Briefing Paper.
INSTITUTION	Appropriate Health Resources and Technologies Action Group (AHRTAG), London (England).
ISBN	ISBN-0-907320-41-4
PUB DATE	1997-00-00
NOTE	66p.
AVAILABLE FROM	Appropriate Health Resources and Technologies Action Group (AHRTAG), Farringdon Point, 29-35 Farringdon Road, London EC1M 3JB, England, United Kingdom.
PUB TYPE	Guides - Non-Classroom (055)
EDRS PRICE	MF01/PC03 Plus Postage.
DESCRIPTORS	*Acquired Immune Deficiency Syndrome; Child Health; Clinical Diagnosis; Developing Nations; *Disease Control; Family Programs; Foreign Countries; *Health Personnel; Health Services; Infants; Intervention; *Outcomes of Treatment; *Prevention; *Symptoms (Individual Disorders); Toddlers; Young Children

ABSTRACT

This briefing paper focuses on children ages birth to five years and is intended primarily for health workers in developing countries who are responsible for the management of young children with HIV and AIDS. It provides practical information on: (1) how HIV is transmitted to infants and young children; (2) how transmission can be prevented; (3) how to diagnose HIV and AIDS in young children; (4) how to care for children with HIV, including treatment of common infections; (5) how to provide support to families caring for sick children; (6) how children who are not infected may be affected by HIV; and (7) how HIV and AIDS in children affects health workers and other caregivers. Other important issues related to HIV/AIDS and children that health workers need to be aware of are also addressed, including community support, orphans, sexual abuse, and HIV testing and counseling. A list of selected printed and organizational resources on AIDS and children is included, along with a glossary of relevant terms. Appendices include a fact sheet on HIV and AIDS and an outline of a workshop and exercises that may be helpful in educating health workers about HIV/AIDS and children. (CR)

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AHRTAG BRIEFING PAPER

Caring with confidence

Practical information for health workers who prevent and treat HIV infection in children

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Acknowledgements

This briefing paper was compiled by Kathy Attawell, consultant, and designed by Ingrid Emsden, AHRTAG Design and Production Officer.

AHRTAG would like to thank the following organisations and individuals for their contribution to this publication: Dr Mazuwa Banda, Dr Simon Mphuka, Karen Sichinga and Catherine Shawa of the Churches Medical Association of Zambia for hosting a workshop on young children and HIV which helped to identify information needs and provide a framework for the development of the briefing paper; Dr Geoff Foster and Dr Connie Osborne who were facilitators at the workshop and provided suggestions for the briefing paper; participants at the workshop who shared experiences and information; Coral Jepson and Jackie Hoskins of AHRTAG's Child Health Programme and Siân Long and Chris Castle of AHRTAG's AIDS and Sexual Health Programme who provided background material and suggestions.

Additional technical information and review has been provided by Harry Campbell (UK), Charles Gilks (UK), Eric Mercier (UNICEF), Angus Nicoll (UK), Eric van Praag (WHO), Felicity Savage (WHO), Sam Kalibala (UNAIDS), Mark Connolly (UNAIDS), David Robinson (WHO), Joanne Manchester (UK), and Jean Emmanuel (WHO).

This briefing paper has been produced as a contribution to the 1997 World AIDS Campaign with the theme 'Children Living in a World with AIDS'. The purpose of the publication is to increase awareness of the issues being faced by children and families affected by the HIV epidemic. Publication and distribution of this briefing paper has been funded by the Swedish International Development Authority (SIDA) and UNAIDS, with additional financial support from the Department of International Development Cooperation, Ministry of Foreign Affairs, Finland, the European Union, and HIVOS (the Netherlands).

Caring with confidence: practical information for health workers who prevent and treat HIV infection in children

Published by the Appropriate Health Resources and Technologies Action Group (AHRTAG), Farringdon Point, 29-35 Farringdon Road, London EC1M 3JB, UK.

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Cover photographs by P Almasy/WHO, Piers Cavendish/SCF, Jeremy Horner and Carolyn Watson/UNICEF.

Layout by Em Associates, London.

Printed by Russell Press, Nottingham.

ISBN 0 907320 41 4

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Introduction

Children worldwide are affected by HIV and AIDS, either because they are infected with the virus themselves or because their mother, father or sibling has HIV infection, or because they are vulnerable to infection.

Until recently, the impact of HIV and AIDS on infants and young children has been a neglected issue. This is because children have been the last to be affected by the epidemic, and because children have little voice in society. In addition, children with HIV often have the same infections as children without HIV, so the extent of the problem in children has been unclear. Access is lacking to basic information about how to prevent HIV infection in children, about diagnosis, treatment and care of children with HIV, in settings with limited resources, and about how to provide support and counselling. There has been little research on the effect of HIV infection in young children and on their families, or on young children who are not themselves infected but where other family members may be infected with HIV and AIDS.

This briefing paper has been developed in response to requests to AHRTAG's Child Health and AIDS and Sexual Health Programmes. It also covers issues and concerns raised by participants at a workshop on AIDS and children held in 1997 in Zambia, who included mothers living with HIV, nurses, paediatricians, midwives, counsellors, and representatives from non-governmental organisations (NGOs). Because children in sub-Saharan Africa have been most affected by HIV / AIDS to date, many of the examples referred to in the briefing paper are from Africa. Other parts of the world, where HIV / AIDS in children is a growing problem, can learn from, use and adapt African experiences.

Greater priority needs to be given to improving the quality of life of children with, and affected by, HIV and AIDS by ensuring that they have access to appropriate treatment, care and support. This means addressing their emotional and psychological needs as well as their physical needs, and ensuring that they are not subject to discrimination, victimisation and exploitation because of their own HIV status or that of members of their family.

The briefing paper focuses on children aged from birth to five years and it is intended primarily for health workers in developing countries who are responsible for the management of young children with HIV and AIDS. It is hoped that the briefing paper will also be of interest to educators, NGOs and those working with community organisations who are involved with HIV prevention and the care of young children with HIV and AIDS.

The paper concentrates on practical information about:

- how HIV is transmitted to infants and young children
- how transmission can be prevented
- how to diagnose HIV and AIDS in young children
- how to care for children with HIV, including treatment of common infections
- how to provide support to families caring for sick children
- how children who are not infected may be affected by HIV
- how HIV and AIDS in children affects health workers and other caregivers.

Other important issues related to HIV / AIDS and children that health workers need to be aware of – for example, community support, orphans, sexual abuse, HIV testing and counselling – are mentioned briefly but not discussed in detail.

There is still much that we do not know about transmission of HIV to children, in particular when it happens and why. This makes it difficult to know how best to prevent transmission. Clinical diagnosis of HIV in children is also difficult because of the overlap with common childhood illnesses. The briefing

paper outlines some of the current debates and unanswered questions, and indicates where more research is needed or is being done. However, health workers should remember two important things, in terms of what they can do. First, the most effective way to prevent HIV in children is to prevent HIV infection in women. Second, care of young children with HIV is based on the same principles as children without HIV – immunisation, good nutrition, preventing infections, and early and effective treatment of common illnesses.

How HIV and AIDS affect young children

This Section describes the impact of HIV and AIDS on young children and the extent of the problem. It also provides an overview of how HIV is transmitted to infants and young children.

HIV and AIDS can affect infants and young children in one of three ways. They may be:

- infected with HIV
- affected by HIV
- vulnerable to HIV.

Children infected with HIV

KEY POINTS

- Children can be infected with HIV through mother-to-child transmission, contaminated blood transfusions, unsterile medical equipment, or sexual abuse.
- A third of babies born to HIV-infected mothers will become infected.
- Children are most affected by HIV in settings where women are most affected by HIV.
- Children with HIV often have the same illnesses as children without HIV, but these may be more serious, frequent or difficult to treat.
- HIV infection is predicted to significantly increase infant and child mortality.

At the beginning of the AIDS epidemic, children were not considered to be at risk of HIV infection. This changed as it became clear that infants and young children had been infected with HIV by contaminated blood transfusions and by use of unsterile medical equipment. It also became clear that the virus could be passed from an infected mother to her baby during pregnancy, birth or breastfeeding.

How are children infected?
Children can be infected with HIV through:

- pregnancy, birth or breastfeeding if the mother is infected with the virus
- receiving infected blood transfusions
- treatment with unsterile medical equipment such as needles, syringes or surgical instruments
- sexual abuse involving penetrative vaginal or anal sex.

Globally, the majority of infected children – about 90 per cent – are thought to acquire the

Facts about HIV/AIDS and children

- Every day an estimated 1,000 children become infected with HIV, mostly in the developing world.
- In 1996, 400,000 children under 15 became infected with HIV. UNAIDS estimates that a total of 2.6 million children worldwide had been infected with HIV by the end of 1996. More than half had died.
- One million children worldwide are HIV positive or have AIDS, most of them in sub-Saharan Africa but with numbers increasing rapidly in South Asia, South-East Asia, Latin America and the Caribbean.
- If current trends continue, between 5 and 10 million children will have been infected with HIV by the year 2000.
- The majority of young children with HIV are infected through mother-to-child transmission, the rest through contaminated blood transfusions and medical equipment, or, more rarely, sexual abuse.
- About four in 10 infected children die by the age of 12 months, many survive beyond two years of age, and some have reached adolescence.

Neil Cooper / Panos Pictures

One-third of children born to HIV-infected mothers will become HIV infected.

virus through transmission from an HIV-infected mother, either during pregnancy, birth or breastfeeding.

Contaminated blood transfusions and medical equipment are thought to be responsible for about 10 per cent of HIV infection in young children. In many countries, children are given blood transfusions to treat anaemia, caused by malaria and other illnesses. Blood transfusions are often given unnecessarily. If blood supplies are not screened for HIV, transfusion with contaminated blood may put children at risk of HIV infection.

A proportion of children with HIV are infected through sexual abuse, although the extent of sexual abuse of under fives and the numbers infected with HIV this way are difficult to estimate.

The relative importance of different modes of transmission in different countries varies depending on the quality of blood transfusion services and health care, and the numbers of women of childbearing age who have HIV infection.

However, in most parts of the world, the number of children with HIV infection is closely related to HIV infection in women of childbearing age. This, in turn, is affected by sexual transmission of HIV between men and women. Not every woman with HIV will pass the virus on to her child. On average one-third of children born to HIV-infected mothers will themselves become HIV infected. (See Section 2 for more detailed discussion of transmission from mother to child.)

Where are children most affected?

Children are most likely to be affected in countries where women are most affected. The number of women infected with HIV, mainly through heterosexual transmission, is rising rapidly throughout the world. It is estimated that for adults:

- in sub-Saharan Africa, half of all those with HIV are women
- in South-East Asia, a third of people infected with HIV are women of childbearing age, and HIV is spreading rapidly
- in the Caribbean, women account for about 40 per cent of HIV infection
- HIV / AIDS is a growing problem in Eastern Europe and the countries of the former Soviet Union, affecting increasing numbers of women.

The proportion of pregnant women who are infected with HIV varies from country to country and between urban and rural areas. In some urban areas of East and Southern Africa, one in three pregnant women is infected with HIV.

Rates of mother-to-child transmission have been shown to range from less than 15 per cent to around 48 per cent. Transmission rates seem to be lower in developed countries than in developing countries.

Lower rates in developed countries may be because of a number of factors, including antiretroviral treatment of HIV-positive pregnant women. Higher rates in developing countries may be because of poorer nutritional and immune status and higher rates of sexually transmitted diseases among women in these countries.

It is also not clear why some babies of HIV-positive women are infected and others are not. There are many unanswered questions about when the infection is transmitted from mother to child, and about the factors which may increase the risk of transmission during pregnancy, birth and breastfeeding. These are discussed in Section 2.

Infants and young children in developing countries with HIV infection also die at a younger age than those in developed countries. This may be because they are exposed to more infections, have poorer medical care and are more likely to be malnourished.

How does HIV/AIDS affect child health?

Although many cases in very young children are not recognised or reported, HIV and AIDS

are major causes of health problems in this age group.

Initially, children with HIV often suffer from the same infections as children without HIV. This is one reason why diagnosis of HIV infection in young children can be difficult. Like other young children, those with HIV and AIDS have common illnesses such as diarrhoea, respiratory infections and malnutrition, but they are more vulnerable to infection and get sick more often. In children with HIV, common illnesses are often more serious, chronic or difficult to treat.

Death rates are also high in children with HIV and AIDS. Estimates vary, but between 10 and 40 per cent of children with HIV in developing countries die before they are 12 months old. Between 50 and 75 per cent die before the age of five years. Because of this, families and health workers may decide it is not worthwhile giving treatment. But effective treatment, preventive care and good nutrition can prolong life and improve quality of life. Health workers should remember that most HIV-infected children survive for more than a year, and up to half survive beyond their fifth birthday.

Rates of illness and death in infants and children are increasing in some countries, reversing many of the improvements in child health which have been made in the past 20 years. Some, although not all, of this increase is due to HIV and AIDS.

It is estimated that HIV could increase infant mortality by up to 75 per cent and under five mortality by more than 100 per cent in countries most affected by the disease. The increases in infant and child mortality rates will be highest in those countries where there are few deaths in infants and young children from other causes – those with lower pre-HIV and AIDS infant and child mortality rates.

1.2 Children affected by HIV

KEY POINTS

- Many children, who are not themselves infected, are affected by HIV and AIDS.
- Loss of a parent or parents affects the emotional, physical and mental health of young children, their security, and educational prospects.
- Children from families affected by HIV/AIDS may be stigmatised and suffer discrimination.

The lives of many children who may not have HIV themselves are affected when family members have HIV and AIDS. Families face increased poverty and stress when adults are too sick to continue with paid employment or to farm their land. Mothers who are ill find it more difficult to care for young children, and young children themselves may end up caring for younger siblings or sick parents.

In addition to children who are living with

Impact of HIV/AIDS on infant and child mortality

It is estimated that:

- In Malawi, HIV infection contributes to 17 per cent of the infant mortality rate (number of deaths of infants under one year of age per 1,000 live births) of 147 per 1,000 live births.
- Without AIDS, Kenya would have an infant mortality rate of 47 per 1,000 live births. With AIDS, the rate has increased to 55.
- In Zambia and Zimbabwe, infant mortality rates are 25 per cent higher than they would be without AIDS.
- Projected infant mortality rates for 2010 for Tanzania and Uganda are 40 per cent higher than they would be without AIDS.
- By the year 2010, deaths due to AIDS will more than double infant mortality rates in Zimbabwe and Botswana.
- Child mortality rates in Kenya and Zambia will double by 2010, to be three times higher in Botswana and four times higher in Zimbabwe. Out of every 1,000 children under five, nearly 100 will die because of AIDS in these countries.
- Child death rates will increase by 14 per cent in Brazil, 20 per cent in Guyana and 7 per cent in Haiti because of AIDS.
- In Thailand, the infant mortality rate will rise by 5 per cent due to HIV/AIDS.

Source: US Bureau of Census.

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Cindy Andrew/UNICEF

Children orphaned by AIDS may be cared for by grandparents.

HIV-infected parents who are sick or dying, there are many who have been orphaned by AIDS. They may have lost a mother or a father or both. It is estimated that:

- nine million children have already lost a mother because of AIDS
- at least 30 million children in the world are living with HIV-positive parents and are at risk of being orphaned in the future
- by 2010, over 40 million under fives in Asia, Africa and Latin America will have lost one or both parents because of AIDS. By 2020, it is predicted that the largest number of AIDS orphans will be in South and South-East Asia
- by the year 2000 in Zimbabwe, 1 in 10 children will have lost one or both parents, and in South Africa there will be 500,000 AIDS orphans. In Thailand, over 200,000 children – a third of them under five – are expected to lose their mothers because of AIDS by 2005.

Loss of a parent or parents can affect young children in many ways. The effects vary from country to country and depend on culture, social and family structures, and legal systems. For example, in some countries, children may lose their rights to property or land. In others, where many children have lost their parents, family support systems are under great strain. Young children may be cared for by grandparents or older siblings who are unable to cope or to afford extra food and clothing, or they may be cared for reluctantly by relatives who already have too many demands. In these circumstances, young children are less likely to be sent to school and more likely to be expected to work at a very young age to contribute to household finances. They may be seen as a burden, especially young girls because they may need to be provided with a dowry or because they will marry out of the family and therefore not contribute financially.

As well as having to cope with loss, grief and confusion, children from families affected by HIV and AIDS may be stigmatised and rejected and not allowed to play with other children. They may be denied health care, either because it is assumed that they too have HIV infection or because carers cannot afford treatment costs.

Young children who are not infected are also more vulnerable to illness and death if they receive less adequate care either because their parents are sick or because their parents have died.

The health of under fives who do not have a mother is generally worse than that of those who do. The mother is relied on to bring a child for immunisations, to seek treatment for childhood illness and to ensure that a child is well nourished. Health education messages about all these issues are usually targeted at the mother. Grandmothers or siblings may know less about good nutrition, have less time, energy or patience to feed a young child or be less able to travel to clinics or immunisation centres. Future health education strategies will need to target a wider range of carers, or larger numbers of children will be at risk of illness and poor health.

Children vulnerable to HIV

KEY POINTS

- Children without parents and displaced children are more vulnerable to rape and sexual abuse, and the associated risk of HIV infection.

Children without parents or who are not living with their parents because of war or economic reasons, are more vulnerable to sexual abuse and exploitation. Refugee and displaced children are particularly vulnerable.

Sexual abuse of children is a taboo subject and rarely reported, and until recently was thought to occur infrequently in developing countries. However, there is growing evidence of very young children being infected with HIV and other sexually transmitted diseases (STDs) following sexual abuse and rape. Although it is usually older children, especially girls, who are most at risk of sexual exploitation, younger children are also vulnerable to sexual abuse.

Often it is only when a child needs treatment for an STD that people become aware that there is a problem of sexual abuse. One study in Zimbabwe found that, in 1990, 907 children aged under 12 years had been treated at the genito-urinary clinic in the capital city, Harare, for STD. In another Zimbabwean study of 54 sexually abused children in Bulawayo, one girl was only two years old. Twelve of these 54 children were tested for HIV and four were found to be positive.

Without family support, education or skills, orphaned children from families affected by AIDS may themselves grow up to be more vulnerable to HIV infection through starting sexual activity at a young age to support themselves. If orphans themselves become HIV infected, they have no parents available to care for them when they are sick or to act as grandparents to their own children.

2 Preventing HIV infection in young children

This Section describes how HIV infection can be transmitted to infants and young children. It also discusses strategies for preventing infection in children, in particular reducing HIV infection in women and reducing transmission through blood transfusions.

2.1 Mother-to-child transmission

KEY POINTS

- HIV can be transmitted from mother to child during pregnancy, delivery or breastfeeding.
- Recent infection or advanced HIV disease in the mother seem to increase the risk of transmission.
- The most effective way to prevent HIV infection in children is to prevent HIV infection in women.

Mother-to-child transmission is the most common way in which infants and young children are infected with HIV. It is important to remember that not all HIV-infected mothers pass the virus to their babies. Two-thirds of babies born to HIV-infected women do not become infected with the virus.

Because most HIV-infected children acquire the infection from their mother, *the first priority in preventing transmission must be prevention of HIV infection in women.* This means strategies which help women to protect themselves against HIV.

How is HIV transmitted to children?

HIV can be transmitted from an HIV-infected mother to a baby during:

- pregnancy
- delivery
- breastfeeding.

During **pregnancy** the baby may be infected because the virus passes through the placenta and umbilical cord or is present in the fluid in the womb (amniotic fluid).

During **delivery** the baby may be infected because he or she is exposed to maternal blood and secretions during labour while passing through the birth canal.

During **breastfeeding** the baby is exposed to the virus in breastmilk.

When is HIV transmitted?

The baby can become infected at any point from early pregnancy until the end of breastfeeding. It is thought that about a third of mother-to-child transmission occurs during pregnancy, and about two-thirds around the time of delivery and afterwards. Figures for the proportion of babies infected during breastfeeding vary, but on average it is thought that breastfeeding is responsible for 14 per cent of mother-to-child transmission.

Risk factors

The risk of *HIV transmission to women* is increased:

- if they have an unrecognised and untreated sexually transmitted disease (STD) (see STD box on page 10)
- by low status and inability to negotiate safer sex
- by inadequate access to information and condoms.

Based on the evidence available, the risk of *HIV transmission from mother to child* seems to be increased by:

- Recent infection in the mother. A woman who has recently been infected has more of the virus in her blood and body fluids.

including breastmilk. (The amount of virus she has is sometimes described as viral load.) So getting infected during pregnancy may increase the risk of transmission to the baby in the womb. Similarly, if the mother becomes infected during delivery (for example, through blood transfusion) or while she is breastfeeding she is more likely to transmit the virus to her baby through her breastmilk. Analysis of a number of studies of breastfeeding and HIV found that the transmission rate was around 14 per cent from mothers who were already HIV positive at delivery. But the rate of transmission from mothers who were infected after delivery during the breastfeeding period was 29 per cent.

- Advanced HIV disease or AIDS in the mother. A woman who has more advanced HIV disease also has a higher viral load and the risk of HIV transmission to the baby during pregnancy, birth or breastfeeding seems to be higher.
- Low birth weight and premature babies. Higher rates of infection may be because their immune systems are not fully developed and they are less able to fight off HIV.

The evidence about other factors which may increase the risk of transmission is not clear. Some studies have suggested that the risk of transmission may be greater if the mother has severe vitamin A deficiency, but more research is needed to determine whether other nutritional deficiencies may also be important.

Other factors being considered that may increase risk include length of labour after rupture of the membranes (the waters have broken), delivery method and practices. But again the evidence is not yet clear and more research is needed.

Preventing and treating HIV infection in women

KEY POINTS

- Empowering women, promoting safer sex, condom (male and female) use, and better detection and treatment of STDs can reduce HIV infection in women and, consequently, reduce transmission of HIV to children.
- Antiretroviral therapy has been shown to reduce mother-to-child transmission of HIV.

This section discusses interventions for which there is evidence that they can reduce mother-to-child transmission of HIV. It also briefly describes potential interventions where more research is needed before we can be clear about their effectiveness in reducing transmission.

Preventing infection in women

The most effective intervention to reduce mother-to-child transmission is preventing infection in women before and during pregnancy and while they are breastfeeding. This is especially important, not only for the health of the woman but also because the risk of transmission to the baby is higher if the mother has recently been infected with HIV.

All women are at risk of acquiring HIV infection from:

- having unprotected sex – penetrative vaginal or anal sex without using a condom
- receiving an infected blood transfusion
- using unsterilised needles and syringes or cutting instruments that are likely to be contaminated with someone else's blood.

Factors which increase HIV risk

Some cultural practices may increase women's infection risk. For example, avoiding or limiting sex during pregnancy or breastfeeding may encourage men to have sex with other partners, increasing the risk that they acquire HIV infection and in turn infect the woman and the unborn child.

Sexually transmitted diseases (STDs) and reproductive tract infections (RTIs) increase the risk of HIV transmission in men and women. Studies have shown that men with untreated gonorrhoea and HIV infection have higher levels of HIV in their semen than men with HIV infection only. Treatment of the gonorrhoea reduces the levels of HIV. STDs associated with ulcers, such as chancroid, also increase the risk of HIV transmission. Better detection and treatment of STDs can reduce HIV transmission between men and women and hence reduce transmission to children.

What can health workers do?

The most important thing that health workers can do is to help women to protect themselves against infection with HIV.

Key aspects include:

- reproductive health services providing counselling, education and condoms, and better detection and treatment of STDs for men and women
- promoting safer sex, for men and women, and norms that support safer sex

Mark Edwards/Still Pictures

Providing young women and girls with the information, skills and means to protect themselves and their unborn children from HIV infection is a key strategy.

- increasing women's skills in sexual negotiation, and providing women with information about HIV and STDs
- promoting women-controlled methods such as the female condom.

Health workers should advise women and men about the risks of HIV transmission associated with unprotected sex, contaminated blood transfusions and use of unsterilised equipment. They should help women in particular to take steps to avoid or reduce the risk of HIV infection before and during pregnancy and while women are breastfeeding.

Avoiding unsafe sex during pregnancy and breastfeeding is the most effective way to reduce the risk of having a child with HIV infection. This means providing young women and girls with the information, skills and means to practise safer sex to protect themselves and their unborn children from HIV infection and other STDs. It also means providing men and boys with information and skills to enable them to practise safer sex. Women cannot easily protect themselves and their unborn children unless men are also aware and concerned about HIV.

Safer sex is any sexual activity that does not involve semen (or blood or vaginal fluid) entering the body or coming into contact with broken skin, and includes:

- using a female condom for vaginal sexual intercourse
- using a male condom for vaginal or anal sexual intercourse

How improved STD control can reduce HIV transmission

- In Kenya, programmes are combining promoting safer sex and syndromic management of STD to reduce HIV transmission.
- A study in Uganda found that HIV prevalence was higher among women with bacterial vaginosis, an STD that can be treated with metronidazole. Bacterial vaginosis (BV) is thought to be a factor in premature birth and premature rupture of membranes, both possible risk factors for mother-to-child transmission of HIV. Treating women with abnormal vaginal discharge for BV as well as gonorrhoea and chlamydia may help to reduce HIV.
- A trial in six villages in Tanzania, in Mwanza Region, showed that better detection and treatment of STD reduced HIV transmission among adults by 42 per cent. The intervention consisted of training health workers in STD syndromic management, making drugs available, and encouraging men in particular to seek treatment. The greatest reduction in HIV and STD was in women aged 15–24 years.
- Another study found that men with gonococcal urethritis had a higher concentration of HIV in their semen than men who had HIV but no gonococcal urethritis. Treating men for gonococcal urethritis (gonorrhoea) reduced the amount of HIV in their semen.

- non-penetrative sex
- oral sex (which still carries a little risk but is much less risky than vaginal or anal sex).

If these options are not possible, health workers can advise pregnant and breastfeeding women to reduce their risk of HIV infection by having fewer partners. STD control strategies to prevent infection and improve detection and treatment of STDs include:

- introducing syndromic management of STD
- promoting safer sex and condom use
- improving partner notification.

If a woman already has HIV infection

If a woman knows that she has HIV infection before she becomes pregnant she needs advice about pregnancy. In some places it may be appropriate for her to receive counselling to help her decide whether or not to have a child. If she decides not to have a child now then she needs advice about contraception and safer sex, and access to contraception.

However, most women in the world do not find out that they have HIV either until they are pregnant, if counselling and testing are available and they decide to have an HIV test, or until after the baby is born and it becomes sick.

Bruce Paton/Panos Pictures

If a woman discovers she is HIV positive during pregnancy, she needs support and counselling.

If a woman discovers that she is HIV positive during pregnancy, she needs emotional support and counselling to help her to decide whether or not to continue with the pregnancy, and continued support during her pregnancy.

HIV and women's reproductive

HIV should never be used as a reason to pressurise women into having or not having children.

Terminating a pregnancy may be an option in some places, if a woman decides not to have a child knowing that there is a risk it may be born with HIV. However, termination of pregnancy may not be a safe option for women in many countries – in many settings abortion is a very risky and dangerous procedure. In some settings termination of pregnancy is illegal, even for women with HIV. In many cultures having a child is very important; a woman who decides not to have a child may be abandoned by her husband and family. Conversely, there is also anecdotal evidence of HIV-infected women being pressurised to terminate their pregnancies because of the risk that the child may be born with HIV.

What can health workers do?

Health workers should ensure that an HIV-positive woman receives advice or counselling and:

- is aware that a third of babies of women with HIV are born with the infection but that two-thirds are not
- understands that, if infected, her baby may be ill, possibly frequently, and may die at a young age, but that she also understands that her baby has a better chance of being well with good treatment, nutrition and care
- decides what she wants to do based on her individual situation and circumstances
- knows where to go for care and support for herself.

Antiretroviral therapy

Infected mothers with more virus in their blood and body fluids seem to be more likely to transmit HIV to their babies. Antiretroviral treatment has been shown to reduce HIV in the body and to reduce mother-to-child transmission.

In a study in 1994 in the USA, researchers found that giving the antiretroviral drug AZT (also called ziduvodine) to HIV-positive women from between 14 and 34 weeks of pregnancy until labour begins and during delivery, and to their newborn infants, reduced HIV transmission by two-thirds. In the control group of mothers, 25 per cent of infants were HIV positive, whereas in the

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group treated with AZT, 8 per cent of infants were HIV positive.

Although AZT was shown to reduce HIV transmission from mother to child, it is no longer recommended alone for treatment in the USA or Europe. Combination therapy – the use of more than one drug to reduce the amount of HIV in the body – has been shown to be more effective than monotherapy (treatment with one drug). Use of only one drug increases the chance that resistance will develop. Babies who have been exposed to AZT but who still acquire HIV have AZT-resistant strains of the virus making subsequent antiretroviral treatment more difficult However, there are still unanswered questions about antiretroviral treatment during pregnancy. It is not clear:

- whether to reduce transmission, pregnant women need to take antiretrovirals throughout their pregnancy or for a short period in the later stage of pregnancy
- how effective antiretroviral therapy is in pregnant women with advanced HIV disease and AIDS
- if there are risks or longer term side effects of antiretroviral treatment during pregnancy for the woman or the infant
- whether giving antiretrovirals prevents transmission during breastfeeding, what effect they have on the amount of virus in breastmilk, or whether breastfeeding should be avoided if antiretrovirals have been used.

At the moment, in most developing countries, antiretroviral drugs are only available to wealthy women or those taking part in clinical trials. Although we know that antiretroviral therapy can reduce mother-to-child transmission of HIV, there are a number of obstacles to making this therapy available to HIV-positive pregnant women in developing countries.

- Antiretrovirals are very expensive. Treatment of a pregnant woman and an infant with AZT costs about US $1,000. Treatment with combination therapy costs more.
- Many pregnant women in developing countries do not know their HIV status. Antiretroviral treatment requires women to take an HIV test early on in pregnancy. Many pregnant women in developing countries currently do not have access to testing and counselling. Some may prefer not to take an HIV test even if facilities are available.
- Women must take the antiretrovirals regularly during pregnancy and intravenously during delivery. Many women in developing countries do not visit clinics regularly during pregnancy or give birth in a health facility. Health facilities may not have the capacity to give intravenous treatment safely.
- One side effect of antiretroviral therapy is anaemia. Women in many developing countries already suffer from anaemia, because of malaria, parasites, poor diet and iron deficiency, and antiretroviral treatment may contribute to severe anaemia. Blood transfusion is the most common treatment given for anaemia. Where blood is not screened for HIV, blood transfusions would increase the risk of HIV transmission to pregnant women and hence to their infants.
- Health workers need education about prescribing and monitoring antiretroviral treatment.
- Even if antiretrovirals prevent HIV transmission during pregnancy or delivery, some infants may subsequently become infected if their mother breastfeeds.
- If antiretrovirals are made available to pregnant women, other women and men with HIV and AIDS would also wish to have access to treatment. In countries with limited resources it may not be possible to provide antiretroviral treatment to everyone who needs it, but justifying only providing it to pregnant women may be difficult.
- And finally, there is the issue of treatment of the woman herself, for the sake of her own health rather than for the purpose of preventing transmission to the baby. Will women have access to antiretroviral therapy after they have given birth?

2.3 Breastfeeding

How do we know that the virus can be transmitted through breastfeeding?

Women with HIV infection have the virus in their breastmilk as well as in their blood. Infants born to women who were HIV negative during pregnancy and at delivery but who were infected through an unsafe blood transfusion at delivery or while they were breastfeeding, have become infected with HIV. For these infants, breastfeeding by a newly HIV-positive mother was the only risk factor.

What is the risk of HIV transmission through breastfeeding?

It is estimated that the additional risk of infection is about 14 out of every 100 breastfed infants – or one in seven – of mothers who are HIV positive.

KEY POINTS

- One in seven babies born to HIV-positive women are thought to become infected with HIV by breastfeeding.
- HIV transmission risk increases if the mother becomes infected while breastfeeding or if symptoms of AIDS develop while she is breastfeeding.
- Improved access to voluntary testing and counselling is important in helping HIV-positive women make an informed choice about infant feeding.
- Once the mother has made a decision about what method of infant feeding is best for her and for her infant, she needs advice about the safest way to do this.

However, a woman who has recently been infected has more of the virus in her breastmilk, and the risk of transmission to the infant is higher if the mother is infected while she is breastfeeding. The additional risk of HIV infection to breastfed infants whose mothers are infected during breastfeeding is thought to be about 29 per cent. However the proportion of women who fall into this category is small, and it is difficult to identify them. It is thus particularly important to advise couples to prevent transmission during the breastfeeding period. Women who have AIDS may also have more virus in their milk and may be more likely to infect their babies.

Larger concentrations of the virus have been found in colostrum than in breastmilk. However, there is no evidence that giving a baby colostrum increases the risk of HIV transmission. It may just be that the virus is easier to measure in colostrum.

Some studies suggest that the risk of HIV transmission continues as long as a baby is breastfed and therefore the risk increases cumulatively the longer the breastfeeding period. Because the risk of not breastfeeding to the baby's health decreases after the age of six months, the relative risk of HIV increases. We need to know more about HIV and colostrum and duration of breastfeeding before any clear recommendations can be made.

Preventing HIV transmission through breastfeeding

Where adequate alternatives are available and the risks associated with artificial feeding can be minimised, HIV-positive women are being advised not to breastfeed because of the risk that infants can become infected through breastfeeding.

Advising HIV-positive mothers about the best way to feed their infants in communities where it is difficult to minimise the risks of artificial feeding is much less straightforward. The current recommendation is that women should be provided with information and helped to make an informed decision about whether or not to breastfeed according to their individual circumstances.

Putting this recommendation into practice is not easy and, for health workers and mothers, there are many issues to consider.

- Breastfeeding protects babies against other infections and is the best and most hygienic form of infant feeding. In countries where malnutrition and infectious diseases are the main cause of infant deaths, not breastfeeding poses a very great risk to infants and young children. Infants who are not breastfed are much more likely to die from diseases such as diarrhoea and acute respiratory infection.
- Breastmilk substitutes – formula or animal milk – are costly to buy. For example, in Zimbabwe, the monthly cost of formula milk for a baby would be around Zimbabwe $250–300, about the same as the monthly minimum wage.
- Safe and hygienic preparation of alternatives to breastmilk require access to adequate supplies of clean water and fuel.
- In places where hygiene is poor and families lack money there may be no adequate alternatives to breastfeeding and it may not be possible to minimise the risk associated with other forms of feeding adequately. The risk to the infant of not breastfeeding in such circumstances is far greater than the risk of HIV transmission.
- In many places there is no access to voluntary testing and counselling and the

R Landy/WHO

Breastfeeding protects babies against other infections.

HIV status of the mother may not be known. If the status of the woman is known, it is difficult to tell whether an infant of an HIV-positive mother has already been infected during pregnancy or delivery. It is also not possible to find out with an HIV antibody test – the most common form of test available – whether an infant of an HIV-positive mother is infected until after the age of 15–18 months. Before that age the baby still has its mother's antibodies, including her HIV antibodies.

What should health workers do?

There are serious concerns that women, including those without HIV, will stop breastfeeding because of fears about transmitting HIV, putting their babies at risk of diarrhoea, respiratory infections and malnutrition. Health workers should remember that most women do not have HIV infection and that not all infants of HIV-positive women will become infected through breastfeeding. They must continue to get across the message that breastfeeding has many benefits and continue to promote it. It will be especially important to continue to promote breastfeeding for women who are HIV negative and to give accurate information at all levels because the issue of HIV transmission can easily undermine breastfeeding.

In the context of HIV, UNAIDS, WHO and UNICEF agree that it is critical to:

- protect, promote and support breastfeeding
- improve access to voluntary testing and counselling
- ensure informed choice about infant feeding for HIV-positive women
- prevent commercial pressures for artificial feeding.

However, in countries where many women have HIV infection and childhood infectious diseases are also common, health workers and mothers face a dilemma about what to do about breastfeeding. A lot will depend on local circumstances. The following steps are intended to help health workers to help mothers to decide what to do.

1. Consider the possibility that the mother may have HIV

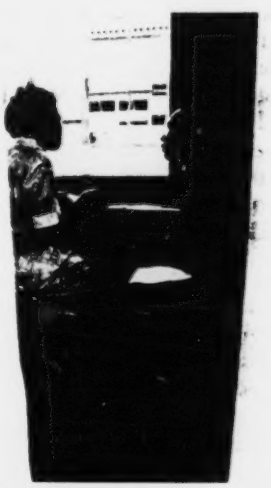
The possibility of HIV infection will depend on how common HIV infection is in your area and on the mother's individual circumstances.

If a mother already knows she has HIV infection, she needs counselling and support to help her consider the implications of being HIV positive and to make a decision about breastfeeding. This includes providing her with information about the benefits of breastfeeding, the risk of HIV transmission through breastfeeding, and the risks and advantages of alternative infant feeding methods.

If a woman's status is not known, she is in good general health and there is no reason to think she has been at risk of HIV, and if there are no voluntary counselling and testing facilities available, it is probably best to assume that she is not infected with HIV and to advise her to breastfeed. It is very important for health workers to explain about the increased risk of passing HIV to the baby if she becomes infected while she is breastfeeding and to advise about preventing infection.

If a woman's status is not known and she is not in good health, it may be helpful for a health worker to assess the possibility that she is sick because of HIV. She may need help to assess whether there is a risk that she may be infected with HIV. This includes the possibility that she may have been infected during pregnancy or delivery. Good counselling is important to help a woman assess whether she has been at risk of HIV infection and to decide whether or not to have an HIV test if voluntary counselling and testing is available.

An important consideration in deciding about testing is whether knowing her HIV status will make a difference to her decision about breastfeeding. In many situations she may have no choice about whether or not to breastfeed. It may be helpful to find out what people usually do if they cannot breastfeed for other reasons.



Jim Holmes/Panos Pictures

If a mother knows she has HIV infection, she needs counselling and support.

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Counselling and testing

Counselling aims to enable a person to cope better with stress, find realistic ways to solve problems and make informed decisions. A counsellor's role is to listen and ask questions, and to provide relevant information, practical suggestions and emotional support. Counselling is not about giving advice or telling people what they should do.

Counselling is an essential part of voluntary and confidential HIV antibody testing programmes. It also plays a valuable role in HIV prevention and care on its own, without testing. Issues such as reducing the risk of infection, family planning, relationships, sexuality and sexual problems, are all important areas for discussion.

Anyone considering an HIV test for whatever reason should always have pre-test counselling, to help assess if he or she has been at risk, learn about the test and its implications, decide whether or not to be tested and think about how to prevent infection. Counselling should mean that a person's consent or refusal to be tested is an informed choice – made freely without pressure, and based on the person's own feelings about the disadvantages and advantages of knowing his or her HIV status.

Consent must be expressed, not implicit. Consent must be specific, not general. A person can give informed consent to an HIV test only after he or she has been given a proper explanation of the nature and likely consequences of taking the test. Informed consent means not only agreeing to the test itself but understanding the implications of a positive or negative test for the future.

Counselling after an HIV test is equally important, whether or not someone is infected with HIV, or if he or she does not want to know the result. One post-test counselling session is often not enough. A person may need on-going support and more sessions.

Confidentiality is an important aspect of a counselling relationship. People are better able to discuss their feelings if they know that the counsellor will not tell anyone else without their permission. Breaking confidentiality can destroy a person's confidence in their counsellor, and expose someone to discrimination at work, or to prejudice from health workers.

While it is vital not to discuss a person's situation without his or her permission, too much stress on secrecy can make it more difficult for the person to cope, and for the most appropriate support to be given. Promoting 'shared confidentiality' means encouraging someone to identify others who are trusted, especially his or her doctor, sexual partner, close friends or family members.

Health workers who may need to counsel women about HIV and AIDS need to:

- know the facts
- listen
- take time
- be concerned
- be available
- establish trust
- be consistent.

Things to avoid in counselling include:

- telling people what to do
- being judgemental
- making promises that cannot be kept
- giving false reassurances
- missing appointments
- doing all the talking
- confusing people with conflicting messages
- using complicated words.

Testing pregnant women

In some countries, pregnant women are routinely offered HIV testing. However, there may be obstacles to overcome to ensure that such testing provides benefits for the woman or the baby.

- Some women will prefer not to be tested or to know their status – they may be afraid to tell their partner if they have a positive result.
- Knowing her status may not affect either the treatment available to the mother or her baby, or her decision about the pregnancy or breastfeeding.
- Many women have little control over their lives and cannot easily make plans for the future.
- Health services may not be able to provide follow-up support and care.
- If the woman is HIV positive it probably means that her partner is too, and this raises issues such as partner notification and couple counselling.

Exercises:

1. What would you want a woman to know about HIV/AIDS if her partner was infected with HIV? How do you think she might feel? Try a role play with a colleague to practise talking about the issues.
2. Think about how women can protect themselves from becoming infected with HIV in your locality. Practise, with a colleague, describing what safer sex means.

2. Help the mother to make a decision about infant feeding

This involves talking to the mother who has HIV about breastfeeding, alternative feeding methods and her individual feelings and circumstances. Based on this, the health worker can help her to weigh up the risks to her infant if she does not breastfeed and the benefits and risks to her infant if she does breastfeed. If possible, and the mother wishes it, the father of the baby should also be involved in the decision.

Deciding whether the chances of HIV transmission are greater or lower than the risks of artificial feeding is the most difficult issue for the health worker and the mother. The following questions are intended to help them reach a decision that is best in the circumstances for the mother and her baby.

What alternatives to breastfeeding are available to the mother?

Are locally available alternatives nutritionally adequate for infants?

- Does the mother have access to a reliable supply of formula or animal milk?
- Is the animal milk sold locally safe or is there a danger than it could be adulterated or diluted? Is it boiled or raw?
- Is wet nursing culturally acceptable? Is there an older member of the family who would be willing and able to nurse the baby?
- Does the mother have access to a breastmilk bank? If so, can it provide milk for long periods of time?

What are her circumstances?

Can the family afford to buy alternatives to breastmilk, not just for a day or a week but for at least six months? Can the family afford to provide adequate complementary foods from six months up to one or two years of age? Are there times of the year when the family has less money?

Will buying formula or animal milk for the baby mean that there is less money to buy food for other members of the family?

- Does the mother have access to a reliable safe water supply? Does she have time to collect the extra water needed?

Does she have fuel or the money to buy fuel to boil water and the baby's feeding utensils?

Does she have the time to prepare milk hygienically and to keep feeding utensils clean?

Does the mother understand that it is safer to feed a baby with a cup and that bottles are much more difficult to clean?

- Does she have support from family and friends to help her feed the baby safely with alternatives?
- Is she well or does she have symptoms of AIDS?

Weighing up the risks and benefits of breastfeeding

- Would the mother's circumstances allow her to minimise the risks associated with alternatives to breastfeeding?
- How common are childhood infectious diseases such as diarrhoea and respiratory infections?
- Is the chance of her passing HIV to her baby through breastfeeding greater or lower than the risks to the baby of alternative feeding methods?
- How does she feel about the risk?
- Does the mother have access to contraceptives to be able to practise family spacing, if she is no longer receiving this protective effect from breastfeeding?

The most important question is probably whether or not the mother's circumstances would enable her to use alternatives

Breastfeeding and HIV: assessing the risk

The following are examples of different scenarios that health workers may encounter in their work. It may be a useful training and support exercise for health workers to discuss together how they would deal with these different scenarios. You can make up different scenarios that are relevant to local circumstances.

- A pregnant woman who knows she is HIV positive approaches you for advice. She has heard that HIV can be passed to babies through breastmilk.
- An HIV-positive woman who chose to give formula to her baby which subsequently failed to thrive.
- A pregnant woman from a poor community who does not know her HIV status but has been told by people in her village that she looked thin and might have AIDS, asks what will happen to her and her baby.
- A woman with a six-month-old son (breastfed and growing well) who recently read that the HIV virus can be spread through breastfeeding. Although she does not know her HIV status, she is worried and wondering whether she should stop breastfeeding.

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Mark Edwards/Still Pictures

Where breastfeeding is the norm, it may be difficult for a woman not to breastfeed.

adequately. If she can, then the risk of death and illness from other infections, as well as from HIV, can be minimised. If she is not able to, then the risks to her infant's health of not breastfeeding are probably greater than the risk from the possible transmission of HIV through breastfeeding.

Having considered all these issues some women may choose not to breastfeed. However, in many communities where families do not have access to clean water and cannot pay for alternatives and where infant mortality from diarrhoea is high, the risk that a baby will die if he or she is not breastfed may be far greater than the risk of HIV transmission. In these circumstances women should continue to be encouraged to breastfeed.

Mixed feeding, that is combining breastfeeding and artificial feeding, is likely to be the worst option – placing the baby at risk both of HIV and of other infections. So, if a mother decides that breastfeeding is the best option in her circumstances, then probably she should be encouraged and supported to breastfeed exclusively. And if she breastfeeds, she should breastfeed exclusively for at least six months, as the risk of childhood infections is especially high in the first six months of life.

Where breastfeeding is the norm, it may also be very difficult for a woman not to breastfeed. She may be asked difficult questions by her family and neighbours and by other health workers about why she is not breastfeeding. As one woman in South Africa said, 'Everyone wanted to know why I was not breastfeeding'. Not breastfeeding may signal to others that a mother has HIV and she may wish to keep her status confidential.

3. Advise the mother about how to feed the infant safely

Once the mother has made a decision about what method of infant feeding is best for her and for her infant, a health worker needs to advise her about the safest way to do this.

If a mother decides to breastfeed, she should be counselled about ways to prevent cracked nipples which may increase risk of HIV transmission. Cracked nipples should not occur if the baby is properly attached at the breast.

If the mother has decided not to breastfeed she needs to be advised about preparing and giving alternatives hygienically to minimise the risks associated with artificial feeding, and about care of the child.

Modified breastfeeding

Two possible options that HIV-positive mothers could consider to reduce the risk of HIV transmission are:

- stop breastfeeding earlier than normally recommended
- breastfeed the baby but stop if she becomes ill with AIDS-related symptoms.

The first approach would mean only breastfeeding for between 6 and 12 months instead of two years, to reduce the length of time that the baby is exposed to the virus in breastmilk. But there are disadvantages of stopping breastfeeding early. The most important is the risk that the baby will not receive adequate nutrition. Preparing other foods for a baby takes time and may also be more expensive for the family. Usually, breastmilk provides about one-third of protein and energy needs for babies between the ages of six months and two years after complementary foods have been introduced. If a baby is no longer breastfed, he or she will need to be given extra complementary foods to make up for the nutrients in breastmilk. Malnutrition is a serious danger to a baby if a family is unable to provide an adequate diet based on complementary foods during this period. The other disadvantage is that the mother only benefits from the contraceptive effect of breastfeeding for a short period of time. Breastfeeding plays an important role in family spacing and if a mother stops breastfeeding earlier she may get pregnant

Alternatives to breastfeeding

Formula milk

Formula milk is the most commonly used alternative to breastmilk. The balance of nutrients is closer to breastmilk than animal milk, but it lacks immunological factors and some essential fatty acids and amino acids. But hygienic preparation and feeding can be difficult and formula is expensive. Feeding an infant for six months requires 44 tins (500g) of formula.

Animal milks

Animal milk such as cow, buffalo or goat's milk are all nutritious and can also be given instead of breastmilk. However, they contain a different balance of nutrients from human milk. Cow's milk is usually the most commonly available alternative, but it needs to be modified to make it suitable for infants. It needs to be diluted to reduce the excess protein and to have sugar added to make sure it has enough energy. Mix one cup of water and three cups of milk with four level teaspoons of sugar. Boil the mixture to kill harmful germs and to reduce the amount of curd.

Whether formula or animal milk are given, a baby needs about 150ml of milk per kg of body weight a day. So a baby weighing 5kg needs five 150ml feeds each day.

Expressed breastmilk

Breastmilk can be expressed by the mother and either boiled or pasteurised to kill HIV. To pasteurise the milk it must be heated to 62.5°C for 30 minutes. Self-help or breastfeeding support groups or health centres may be able to help mothers to express and treat their breastmilk. This is being done by HIV-positive women's self-help groups in Brazil, for example. However, continuing to express and treat breastmilk for a long period of time may be difficult. Also, expressed and treated milk needs to be kept in a refrigerator to stop it going bad.

Wet nursing

In some places it may be acceptable for a woman other than the mother to breastfeed the baby. Care is required in selecting a wet nurse and this option is not advisable if there is a risk that she may herself be HIV positive. In some settings, grandmothers have been acceptable wet nurses, and this might be an approach to encourage, since grandmothers will have low HIV risk and where this is a traditional practice it will be acceptable.

Breastmilk banking

Another alternative is giving the infant donated breastmilk which has been pasteurised and stored at a breastmilk bank. However, it is important to be sure that the breastmilk bank screens donors and donor milk for HIV and other possible infections. Milk banks are rare in most countries and, in addition, they are generally used as a source of milk for short periods of time so are not an option for providing an infant with all his or her nutritional needs for a longer time. This option may be useful for low birth weight babies until they are large enough to be fed on formula.

again more quickly – this has implications for the health of the mother, older children and the next baby.

Reducing the risks associated with giving alternatives to breastmilk

To prepare and give formula or animal milk feeds, mothers need to:

- first wash their hands with soap and water
- wash the mixing and feeding vessels with boiled water or boil to sterilise them before preparing the milk and feeding the infant
- feed the infant using a cup. Cups are easier to sterilise than bottles. Bottle-feeding should be avoided because it increases the risk of diarrhoea.

Health workers should show mothers how to prepare and give alternatives and then watch them do it themselves to make sure they can do it correctly.

Complementary feeds must also be hygienically prepared and given with a clean cup, otherwise the infant is at increased risk of diarrhoea.

4. Follow up the infant's growth and general health

Babies who are not breastfed, or who stop breastfeeding early, are more likely to develop malnutrition. Their growth should be checked carefully to make sure they are gaining weight. If an infant is not growing properly, the health worker needs to check that the mother is giving the correct amount of formula or animal milk.

Diarrhoea is also more likely, so health workers should make sure that mothers know how to treat diarrhoea and have access to oral rehydration salts (ORS) or can prepare suitable safe home fluids.

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2.4 Other interventions to reduce transmission

KEY POINTS

- Encouraging and enabling better nutrition among pregnant women, whatever their HIV status, is important.
- Use of sterile instruments, avoidance of unnecessary procedures, and introduction of other safe delivery practices, whether at home or in health care facilities, can reduce HIV transmission during delivery.

Other interventions to reduce mother-to-child transmission are being explored but there is not enough information available yet to be sure whether these are useful. The latest information about these potential interventions is discussed briefly below.

Improving nutrition during pregnancy

Many women in developing countries are undernourished. The risk of transmission to the baby from a mother with HIV infection may be increased if she does not have enough to eat or does not eat enough of the right foods.

One theory being explored is that HIV-positive women who are deficient in vitamin A during pregnancy may be more likely to transmit the virus to their unborn child.

Vitamin A deficiency in pregnancy is common in developing countries. Causes include depletion of the body's stores of vitamin A because of pregnancy itself and because of infections, poor diet with insufficient foods containing vitamin A, and not absorbing enough of the vitamin from food. Women with HIV may be more deficient because they have more frequent illnesses and opportunistic infections.

A study of HIV-positive women and their infants in Malawi found that HIV transmission rates were higher from mothers with vitamin A deficiency. The risk of HIV transmission increased as vitamin A deficiency increased. Women with severe deficiency were three or four times more likely to have HIV-positive babies. Also, babies born to mothers with the most severe deficiency were more likely to die. Possible explanations for this include:

- Vitamin A helps to maintain the immune system and the internal surfaces of the body such as the birth canal. So maternal deficiency may weaken the birth canal, increasing the chance of tearing during delivery and as a result increasing an infant's exposure to maternal blood.
- Vitamin A deficiency may allow more of the virus to be present in breastmilk. A study in Kenya found higher concentrations of HIV in the breastmilk of positive women with vitamin A deficiency.

But there is no conclusive evidence as yet. In South Africa, Zimbabwe, Malawi and Tanzania researchers are looking at whether daily vitamin supplementation of different combinations of vitamins during the last six months of pregnancy reduces mother-to-child transmission of HIV.

Malnourished women and those with poor diets are often deficient in other vitamins and minerals, such as vitamins B6, B12 and E and copper and zinc, as well as in vitamin A. So, it is possible that higher risk of transmission may be because of deficiencies in a range of important vitamins and minerals rather than just a lack of vitamin A.

What can health workers do?

It is too early to say whether HIV-positive pregnant women should receive supplements of vitamin A or other vitamins. The most important thing that health workers can do is to promote better nutrition among all pregnant women, regardless of their HIV status. Health workers need to be aware of cultural beliefs that may restrict what pregnant women can eat.

Jeremy Hartley / Panos Pictures

Health workers can promote better nutrition among all pregnant women.

Jorgen Schytte/Still Pictures

Delivery needs to be as safe as possible for the mother, the baby and the birth attendant.

If a health worker knows that a pregnant woman has HIV infection, it is important to encourage her to eat enough foods which are rich in vitamin A such as:

- animal products such as milk, liver, kidney, eggs, butter and ghee
- orange and yellow fruits and dark green leafy vegetables such as mangoes, papaya, pumpkin, carrots, maize, yellow sweet potatoes, bananas, spinach, amaranths, kale and the leaves of cassava, cowpeas, sweet potatoes and beans
- vegetable oils such as red palm oil.

Note: If the mother has too much vitamin A it can be dangerous for the unborn child. Excessive dosages (greater than 15,000 IU/day) should not be given.

Medical procedures during pregnancy and delivery

Invasive procedures during pregnancy such as amniocentesis (taking a sample of the fluid surrounding the baby in the womb), cordiocentesis (taking a sample of the umbilical cord that joins the baby to the placenta), or taking a sample from the placenta, should be avoided unless they are essential to save the life of the mother or the baby, because of the theoretical risk of increasing HIV transmission.

It is not clear how or why HIV is transmitted from mother to child during or around delivery. Theories suggested include

Safe delivery at home

Many women in developing countries give birth at home. Health workers and birth attendants can help to reduce HIV transmission during delivery at home by using sterile instruments and following good hygienic practices. Health workers or birth attendants can prepare or advise the family to prepare the following:

- several large pieces of clean cloth for wiping and wrapping the baby
- two clean ties or threads for tying the umbilical cord
- one clean new razor blade for cutting the cord
- one container of antiseptic solution such as gentian violet or iodine solution
- cotton wool or clean cloths for applying antiseptic solution to the cord stump
- gloves or plastic bags for the birth assistant and for handling the afterbirth
- one container of clean (boiled and cooled) water for cleaning the mother, the baby and the birth assistant's arms
- soap
- pads or clean cotton cloth for the vaginal area to catch bleeding after the birth.

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contact with HIV-infected blood and maternal fluids, and practices during delivery involving the use of sharp instruments.

Whatever the reasons, delivery needs to be as safe as possible for the mother, the baby and the birth attendant. Precautions to prevent transmission to health workers are discussed in Section 4.

Length of labour after rupture of the membranes may affect the risk of HIV transmission to the baby from an infected mother because the baby is exposed to maternal blood for a longer time. Different studies have shown conflicting findings. However, it is probably advisable to avoid artificial rupturing of membranes because of the increased theoretical risk.

In Malawi, washing the birth canal during labour with a solution which kills the virus, to reduce the infant's exposure to HIV, was studied. The procedure involved manual cleansing of the birth canal with a solution of 0.25 per cent chlorhexidine gluconate in sterile water. Chlorhexidine was used because it has a good safety record and can neutralise HIV. The results showed that mother-to-child transmission was reduced by about a third in women whose waters broke more than four hours before delivery, but there was no difference when delivery took place less than four hours after the waters had broken. However, there were other advantages including reduction in other infections, such as streptococcus B. More research is needed to assess the value of this procedure before it can be recommended.

Because exposure to maternal blood in the birth canal during delivery is thought to be responsible for HIV transmission in infants of HIV-positive mothers, researchers have compared rates of transmission between babies delivered vaginally and those delivered by caesarian section to see if caesarian delivery reduces the risk. Caesarian delivery is when an operation is performed to remove the baby from the mother's abdomen. Like studies on length of labour, the findings are conflicting and there is no conclusive evidence that method of delivery makes any difference to the risk of HIV transmission from mother to child. In addition, caesarian section is a very risky procedure for women.

Many women are given an episiotomy (a cut is made to the entrance to the birth canal) when they are in labour to help them deliver the baby and to prevent tearing. This practice should be avoided as there is no evidence that an episiotomy leads to an easier delivery, and it may theoretically increase risk.

2.5 Transmission through blood transfusion

KEY POINTS

- If blood is not screened for HIV, blood transfusions given to either women or children carry a risk of HIV transmission.
- Reducing the use of blood transfusions and improving the safety of blood supply are key measures to reduce the risk of HIV transmission.

Ron Giling/Panos Pictures

If blood is not screened for HIV, a transfusion increases the risk of infection.

All women lose some blood during delivery. Although normal blood loss during delivery can be made up by the woman's body after birth if she eats a good diet, in some places blood transfusions are routinely given to women to replace blood losses. If the blood is not screened for HIV, a transfusion increases her risk of infection. And if she becomes infected, she may transmit the virus to her baby during breastfeeding.

Infection through blood transfusion now mostly happens in countries with limited resources where the blood supply is not screened for HIV, where HIV infection rates among blood donors are high and where equipment used for giving transfusions is not properly sterilised.

Blood should be screened for HIV and transfusions only be given to women who have severe life threatening haemorrhage during or after birth.

The need for transfusions can also be reduced by giving pregnant women iron supplements, ensuring that they eat iron-rich foods to prevent anaemia, and by treating malaria and parasitic diseases which also cause anaemia. Women who are not anaemic are less affected by blood loss during delivery.

In some countries, transfusions are routinely given to children as treatment for malnutrition, malaria and sickle cell anaemia. Where blood is not screened for HIV, children receiving transfusions are at risk of HIV. In some South-East Asian countries such as India and Pakistan, children may be at high risk of infection because the blood supply relies on commercial blood donors and is not screened for HIV in every health facility. For example, in Pakistan, it is estimated that 40 per cent of blood is not screened for HIV.

Preventing transmission through blood transfusion

There are two strategies for preventing transmission through blood transfusion:

- reducing the use of blood transfusions
- improving the safety of the blood supply.

Reducing use of transfusions

The use of blood transfusions can be reduced by:

- ensuring that the transfusion is really necessary; this means only giving a transfusion when it is essential to save a patient's life
- developing precise guidelines for giving transfusions to children and women, especially pregnant and lactating women, and to patients with severe blood loss
- ensuring that health workers provide clear reasons when prescribing blood transfusions on a request form
- providing training for staff and monitoring blood use
- using blood substitutes for volume replacement where possible to replace fluids after haemorrhage
- not using 'top ups' of blood as a 'tonic' when someone is weak from anaemia or after delivery
- preventing and treating illnesses in children and women that lead to anaemia such as malaria, parasitic infections and malnutrition; this includes encouraging community-based programmes to prevent and treat malaria and worms
- treating the underlying cause of anaemia
- preventing and treating anaemia in pregnant women by giving iron supplements or encouraging them to eat iron-rich foods.

Improving the safety of blood supply

Blood transfusion services can maximise the chances that the blood supply is safe by:

- setting up a donor selection process to identify and retain safe blood donors
- training staff in education and counselling skills
- ensuring that there is a regular and adequate supply of equipment for collecting, screening and storing blood
- testing (screening) all donated blood for HIV (and other infectious agents) and disposing safely of infected blood
- ensuring that there are adequate facilities for safe storage of blood (blood cold chain)
- developing and implementing quality control measures
- educating prescribers of blood and blood products about correct indications for use
- ensuring accessibility of alternatives to blood.

The most effective way to ensure safe blood supply is encouraging people at low risk of HIV infection to be voluntary unpaid blood donors and counselling them about the need to be responsible donors and about safe sex. Counselling potential donors also includes encouraging those who may have been at risk of HIV not to give blood.

Using donors who are paid increases the risk of unsafe blood donation. People who sell their blood are often those most at risk of communicable diseases including HIV.

In rural areas where blood supplies are

scarce, family members may be asked to donate blood. But this can be risky in areas where many people are infected with HIV.

Acquired infection

KEY POINTS

- Some children have been infected through surgical instruments, needles and syringes that have not been properly sterilised.
- Children can also become infected through sexual abuse involving penetrative sexual intercourse.

Transmission of HIV through medical equipment can be prevented if health workers follow standard guidelines for sterilisation of reusable equipment between patients or use disposable needles and syringes.

Dealing with the issue of possible transmission through sexual abuse is more difficult. Sexual exploitation of children is often a taboo subject and people usually do not believe that it could happen in their culture or their community. However, it is clear from cases of STD that children, even very young children, are subject to sexual abuse, by family members, neighbours and strangers, but health workers do not always pick up on the signs.

If they are able to through their work, health workers should try to raise awareness of the issue and of the risk it poses to children. They will need training to help them know when to suspect that a child is being or has been sexually abused, who to talk to and how to raise the subject, how to examine children for signs of sexual abuse, and what other agencies need to be involved.

Diagnosis, treatment and care

This Section describes how HIV and AIDS affects children's health and issues related to diagnosis in young children. It provides a practical overview of management and care for children with HIV and AIDS at community and primary care levels, including prevention, supportive care, treatment of common illnesses and referral. Finally, it discusses care for children affected by HIV and AIDS.

Diagnosis and testing of infected children

KEY POINTS

- Many HIV-infected children die from common childhood illnesses.
- Diagnosis of HIV in young children is often based on clinical signs. However, clinical diagnosis is difficult.
- Where available, an HIV test can confirm the clinical diagnosis.
- Counselling for family members and children should precede and follow any diagnostic tests.

HIV infection is a chronic condition which ranges from no symptoms to AIDS.

Infections in HIV-positive children are usually caused by the same pathogens as in HIV-negative children, but tend to be more frequent with repeated infections more common. Children with HIV also have a greater risk of pulmonary tuberculosis. However, infections in HIV-positive children can sometimes be caused by more unusual opportunistic infections which respond poorly to treatment.

In general, the management of specific conditions in HIV-infected children is similar to that in other children. Many HIV-infected children die from common childhood illnesses, rather than from AIDS. Most of these deaths are preventable by early diagnosis and correct management of childhood infection. Ensuring that all children get the best practical treatment for common illnesses is the best way of caring for children with HIV.

Although some children with HIV stay well for many years, especially if they receive good nutrition, treatment and care, some become sick and develop HIV disease and AIDS-related symptoms soon after HIV infection. These children may get sick more quickly than adults who can be free of symptoms for many years. This is possibly because an infant's immune system is not fully developed and is less able to fight the virus.

Children may also die more quickly than adults after becoming infected with HIV. Worldwide, about half the infected infants will die before the age of five years.

Children with HIV infection in developing countries become ill and die more rapidly than those in industrialised countries, because of lack of appropriate treatment and care, poor nutrition and infectious diseases to which they are very vulnerable. In Zambia, for example, nearly half of infected children die before the age of two, and in one Ugandan study two-thirds had died by the age of three.

Diagnosis

HIV in infants and young children is diagnosed on the basis of clinical signs confirmed by diagnostic testing. In many countries, clinical diagnosis alone is used because laboratory testing is expensive or not available, and because HIV antibody testing – the most commonly used method – does not give a true picture of a child's HIV status before the age of 15–18 months. A definitive diagnosis of HIV, if it is made at all, is most likely to be made at referral level.

Clinical signs and symptoms

The clinical expression of HIV infection in children is highly variable. A proportion of HIV-positive children develop severe HIV-

TALC

In developing countries children with HIV often have the same illnesses as children without HIV infection.

related symptoms in the first year of life; these signs are associated with high mortality. Other HIV-positive children may remain asymptomatic or mildly symptomatic for more than a year and may survive for many years.

Symptomatic HIV infection

In developing countries, children with HIV often have the same illnesses as children without HIV infection and, like children without HIV, are killed by common infections such as diarrhoea, measles and respiratory infections.

This makes clinical diagnosis of children with HIV difficult and, without access to laboratory testing, health workers may not be able to distinguish HIV-positive children from other children.

However, unlike other children, infants and children with HIV infection may have:

common illnesses that are more severe, more frequent and more persistent

recurrent serious systemic bacterial infections

opportunistic infections.

HIV-positive children have symptoms which include failure to thrive, wasting, weight loss, persistent and recurrent diarrhoea, repeated attacks of oral thrush, otitis media and skin rashes, recurrent fever and delayed development.

In addition, they may not respond so well to standard treatment and are also more likely to suffer from recurrent or serious bacterial infections with life-threatening conditions such as septicaemia, meningitis and abscess.

Signs

The following signs are less common in children without HIV:

- recurrent infection – more than two severe episodes of a bacterial and/or viral infection (pneumonia, meningitis, sepsis, cellulitis) in the past 12 months
- oral thrush – the presence of white plaques (spots) inside the mouth. After the neonatal period, the presence of oral thrush without previous antibiotic treatment or lasting more than 30 days despite treatment, is highly suggestive of HIV infection

herpes zoster – also known as shingles, a skin condition characterised by a painful rash with blisters confined to one part of the body

- chronic otitis media – ear discharge lasting 14 days or more

chronic parotitis – the presence of swollen glands just in front of the ear for 14 days or more. There may or may not be any associated pain or fever and the swelling may be on one or both sides

- generalised lymphadenopathy – the presence of enlarged lymph nodes without any apparent underlying cause
- persistent and/or recurrent fever – fever (over 38°C) lasting for seven days or more, or occurring more than once over a period of seven days

neurologic problems – development delays, failure to reach developmental milestones.

The following two signs are common in non-HIV-infected children as well as in HIV-positive children:

- persistent diarrhoea – diarrhoea lasting 14 days or more
- failure to thrive – a marked downward change in expected growth as indicated on the child's growth card.

Conditions specific for HIV infection in children

The following conditions are known to be very specific to HIV-infected children. However, diagnosis of these conditions is difficult with limited diagnostic facilities.

- Pneumocystic carinii pneumonia (PCP) – a diagnosis of PCP should be made in a child who has severe or very severe pneumonia and filling up of the small spaces in the lungs revealed by chest x-ray. The possibility of PCP should also be considered in children known or suspected to have HIV with ordinary pneumonia but who are not responding to treatment.
- Oesophageal candidiasis – the child may have difficulty or pain while vomiting or swallowing, reluctance to take food, salivation, crying during feeding and weight loss. The condition may occur with or without evidence of oral thrush. If oral thrush is not found, other causes of painful swallowing (such as cytomegalovirus, herpes simplex, lymphoma, carcinoma and, rarely, Kaposi sarcoma) may have to be ruled out, usually at a higher referral level.
- Lymphoid interstitial pneumonitis – the diagnosis of lymphoid interstitial pneumonitis (LIP) is difficult. In general it requires confirmation by a chest x-ray. The child is often asymptomatic in the early stages but may later have a cough, with or without difficulty breathing and signs of hypoxaemia such as finger clubbing.
- Kaposi sarcoma – this is rare in children. Diagnosis needs to be confirmed by skin biopsy.

There are problems with using clinical symptoms as the basis for diagnosis of HIV in children.

- Clinical diagnosis is difficult, because many of the signs are common in children whether they are infected with HIV or not. For example, children with tuberculosis who do not have HIV fail to gain weight, have intermittent fever and chronic cough. Children with HIV who do not have TB have the same symptoms.
- The clinical criteria therefore lack specificity (some children may be diagnosed as infected when they are not) and sensitivity (some children who are infected may not be diagnosed as having HIV).
- The emphasis on chronic illness means that acute illnesses, which also contribute to death in infants and young children with HIV, may be missed.
- Some illnesses are more difficult to diagnose in children with HIV. For example, children with HIV who have tuberculosis may be tuberculin test negative because their immune system is not functioning well, and may have different symptoms such as fever without a cough.

HIV counselling and testing

If the child's HIV status is not known, but there are reasons to suspect HIV infection (based on clinical signs or diagnoses in the family), WHO and UNAIDS recommend that the child should be tested for HIV where possible. Although maternal antibodies interfere with conventional serological testing under the age of 15 months, if the child is suspected to have HIV on clinical grounds, WHO suggests that both the mother and child should be tested to rule out other HIV-associated and potentially treatable clinical

Birth to 6 months

A few babies with HIV are small at birth and fail to thrive. Many develop symptoms at about three or four months of age. These symptoms may include severe bacterial infections (such as meningitis, severe skin infections or itchy rashes, pneumonia), swollen lymph glands in the neck or under the armpits, swollen stomach (because of enlarged liver or spleen), failure to thrive, and fungal infections, especially oral thrush. Babies may also cry constantly or be irritable.

Six months to 15 months

Growth faltering, often with illnesses such as malaria, diarrhoea or ear infections (otitis media), is common. Persistent diarrhoea and respiratory (cough) and lung (pneumonia) infections may also be frequent. Babies may also be slow to crawl or unable to sit.

Over 15 months

In addition to the symptoms in children aged 6–15 months, those aged over 15 months may also have itchy rash (eczema), swollen glands, chronic cough and persistent oral thrush. They may be slow to start walking or talking. Upper respiratory infections may become chronic and otitis media may develop into mastoiditis.

Issues to consider in testing children for HIV

- Antibody testing an infant before the age of 15 months will only provide information about the HIV status of the mother. If other methods (such as polymerase chain reaction – PCR) are available for testing the child, ask whether the parents want to know the child's HIV status or is it the health worker that wishes to know.
- Are pre- and post-test counselling available to the mother and other family members to help them understand the implications of testing the child and to make an informed decision? Testing the child should never be used as a means of indirectly testing the mother.
- Are staff available who have the training and skills to counsel parents if their child is discovered to have HIV?
- If a child is found to be positive, will this help the child to get the special care and attention he or she needs? For example, will infections which could become serious such as diarrhoea or pneumonia be identified and treated more quickly?
- Is there a danger of discrimination against the infant if he or she is diagnosed as HIV infected?
- Will it help parents to know why the child is frequently sick? Will it prevent them spending money and time seeking a cure?
- Is there a danger that, if they do not know the child has HIV, they may believe that immunisation or ORS do not work and may fail to give these to their other children?
- Will knowing the child's HIV status change your advice to parents about care of the child including preventing infections and seeking help promptly from a health worker if the child becomes sick?
- Is it possible to refer the mother and child for support and counselling or to a community care programme?
- Because diagnosis of HIV in a child probably means that the mother also has HIV infection, and possibly also the father, what implications will this have for the family?

problems such as tuberculosis. In addition, if it is known that the mother became infected after delivery, the presence of antibodies in the first year of life are indicative of HIV infection in the infant.

An HIV test can confirm the clinical diagnosis, alert the health worker and parents to HIV-related problems, and discuss prevention of mother-to-child transmission (including where possible prevention using antiretrovirals). If the child does have HIV, the parents and child will know why the child is frequently sick, and parents will know how to manage the child. In theory the child can also be referred to appropriate facilities, for support, counselling and treatment or for home-based care. However, health workers need to decide whether testing the child and discovering that he or she has HIV infection provides any benefits, and what impact a positive test result would have on the mother and other members of the family. Issues to be considered are included in the box above.

In settings where there is no access to HIV testing, health workers must assess the possibility that the child has HIV on the basis of clinical signs and symptoms. They should also remember that treatment and care of common infections is the same in all children, regardless of HIV status, but that they should be alert for children who respond poorly to standard treatment or have frequent or more severe infections.

Counselling both before and after testing is essential. HIV counselling should take account of the child as part of a family, including the psychological implications of HIV for the child, mother, father and other family members. Counselling requires time and needs to be done by knowledgeable staff. Staff at first referral level may not have sufficient experience to provide counselling. If the first level health worker is not doing the counselling, the reason for referral to counselling should be discussed with the parent.

HIV counselling is indicated in the following situations, if a child:

- has an unknown HIV status and presents with clinical and/or epidemiological risk factors
- is known to be HIV positive and is responding poorly to treatment or needs further investigations
- is known to be HIV positive and has responded well to treatment prior to discharge and referral to a community-based care programme for psychosocial support.

In children with an unknown HIV status:

- manage emergency conditions if present (the treatment is the same for HIV-infected and uninfected children)
- manage other associated conditions

- decide if you will do the counselling or need to refer the child
- if a health worker is doing the counselling, then he or she needs to make time for the counselling session, and the following should be considered during the counselling session:
  - reason for considering HIV infection
  - HIV transmission routes in children, prevention of transmission in a family setting
  - management and follow-up issues
  - risk factors for illness
  - immunisation and HIV
  - breastfeeding and HIV
  - how the HIV test is done
  - the implications of a positive result in the child and/or parents.

In children who are known to be HIV positive and respond poorly to treatment or need further investigations, the following discussions should form part of the counselling sessions:

- the parents' understanding of HIV infection
- management and follow-up
- risk factors for illness
- immunisation and HIV
- the need to refer to a higher level.

In children who are known to be HIV positive and respond well to treatment prior to discharge and referral to a community-based care programme for psychosocial support, the following discussions should form part of the counselling session:

- the reason for referral to a community-based care programme
- management and follow-up
- risk factors for illness
- immunisation and HIV.

Diagnostic tests

There are several diagnostic methods for detecting HIV in infants and young children, including testing for HIV antibodies, viral culture and polymerase chain reaction (PCR) testing.

HIV antibody testing

Antibody testing is the most common and widely available method for diagnosing HIV. An HIV test – usually an ELISA (enzyme-linked immunosorbent assay) test – detects antibodies to HIV in the blood. These antibodies are produced by the body's immune system in response to infection with the virus.

Ron Giling/Panos Pictures

Antibody testing is the most widely available method of diagnosing HIV.

If there are no antibodies, the person is antibody negative (seronegative or HIV negative). In adults, the test may be negative if they have only recently been infected because it can take up to three months from the time of infection before antibodies are produced. This is called the 'window period'.

In infants and young children, antibody testing is more complicated. This is because a child is born with his or her mother's antibodies which can remain in the child's body until about 12–15 months of age. Hence, during the first 15 months of life, an antibody test cannot show a difference between maternal antibodies and those produced by the baby. It is only possible to tell whether or not a baby is infected once his or her own immune system takes over and the maternal antibody is gone.

Other diagnostic methods

These methods look for the presence of the virus itself rather than the body's reaction to it. Virus culture from blood or body fluid or PCR can detect whether or not an infant is infected with HIV in most cases by the age of about three months.

But these methods are expensive, require sophisticated facilities and expertise, and are not usually available in developing countries.

Treatment and care

KEY POINTS

- Good care and treatment improves the quality of life for children with HIV.
- Providing supportive care at home may be less expensive for the family and more familiar and happier for the child.
- Providing regular, nutritious food helps the child grow and fight off infections.
- Children with HIV are not sick all the time and should lead as normal a life as possible.

Most HIV-related illness in children is caused by common infections that can be prevented and cared for at home or treated at a health centre. Early recognition and treatment of common illnesses can also prevent the development of more serious infections, reducing hospital admissions and demand on health services. This section therefore focuses on:

- prevention, treatment and supportive care at home
- management of common infections at primary care level
- referral of more serious illnesses and children who fail to respond to standard treatment.

Good care and treatment can improve the quality of life and life expectancy for children with HIV. Most early deaths are preventable with good management. But in many settings, health services are unable to provide the ongoing care that children with HIV and AIDS need at health facilities.

Some countries have adopted a 'continuum of care' approach. This covers a range of services including counselling and testing, clinical treatment, and community- and home-based care. Care is provided at different levels and at different times according to need. The key to improving quality of life for children with HIV is early entry into the continuum of care.

In Zambia for example, a number of different 'entry points' are used to ensure that those who need care are identified, including blood transfusion services, traditional healers, NGOs, counselling and testing facilities, and community-based home care programmes. Care is provided at different levels, according to severity of illness, and whether the child can be looked after at home or needs to be admitted. Steps are taken to make sure that proper care can be provided after discharge from a health facility.

P Almasy/WHO

Parents and caregivers need information about looking after children with HIV.

Basic care and support needs for all children – with and without HIV

- Nutrition – safe weaning and nutritious food
- Care – consistent parenting, security and love
- Recreation – something and someone to play with
- Education – parents and caregivers need information about looking after children when they are ill
- Prevention of illness – immunisation, good hygiene and a safe environment
- Appropriate management of illness – treatment and supportive care for common infections.

Prevention, treatment and supportive care at home

Caring for children with HIV at home has several advantages:

- good basic care can be given at home
- sick children are usually happier at home in a familiar environment and surrounded by their family and friends
- it is usually less expensive for families to

care for a sick child at home, with fewer hospital bills and transport costs
- carers can more easily meet other family responsibilities.

No family will have a health worker with them all the time to help with the care of a sick child. Families are important members of the health team and health workers need to teach them about HIV and home care.

Families need to know how HIV is transmitted and not transmitted, what they can do to prevent transmission of HIV and other infections and to keep their child well, how to recognise and take care of common illnesses, and when a child is more seriously ill and needs to be taken to a health facility.

As a health worker, think about who needs to know about home care and what they need to know. Talk to them about caring for the child at home. Find out what they already know. Let them ask questions and answer their questions. Check that they understand what to do and that they have the time and resources to care for the child. Help them to identify other people who can help them and provide support.

Some projects have provided simple home kits – which include, for example, items such as soap, bleach, vaseline and ORS packets – to help families to care for children with HIV and AIDS.

Preventing transmission of HIV at home

There is very little risk that carers will acquire HIV from looking after a child with HIV or AIDS, provided that they follow certain simple rules.

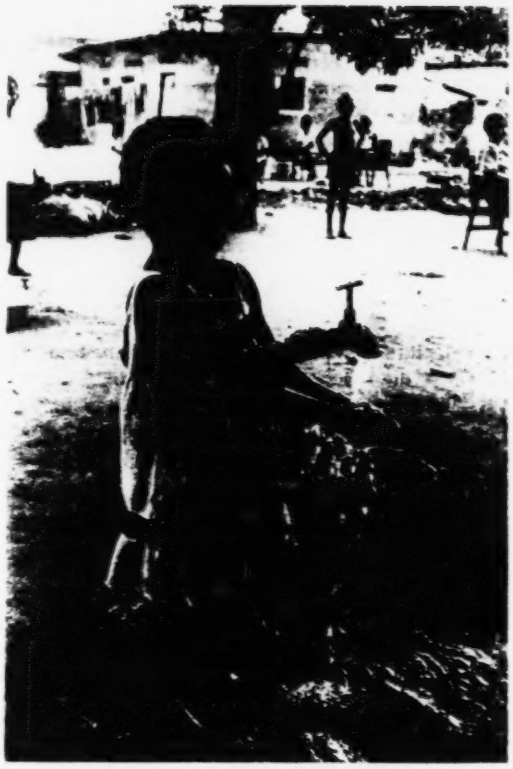
These include minimising contact with blood and body fluids, being careful with sharp instruments and covering open cuts and wounds. Bed linen and clothing soiled with faeces or blood should be washed carefully with hot water and soap and handled as little as possible.

Helping children to stay well

The following are some of the most important things that parents can do to prevent illness and help their children to stay well, whether or not a child has HIV infection.

Hygiene

- Make sure the home is clean.
- Prepare food and drink, including formula, hygienically with boiled water and clean utensils.
- Wash hands with soap (or ashes) before preparing and giving food to the child, after using the toilet and after changing soiled bedding or clothes, and before giving medicines.



Diyawanga/WHO

Frequent handwashing helps prevent illness.

- Teach young children to wash their hands frequently, especially after using the toilet and before eating.
- Keep the child away from animal and human faeces, and keep areas where children play as clean as possible.
- Brush the child's teeth until he or she can do it.
- Wash the child's bed linen, towels and clothes with hot water and soap. Keep separate from other household laundry if blood or faeces are on them, avoid touching blood or faeces by rinsing off first and then wash items in hot soapy water and dry in the sun. Wash hands after handling soiled articles.
- Avoid spitting (this spreads TB) or spit into a container.
- Cover your mouth when coughing or sneezing.
- Dispose of waste, in a pit latrine or by burying or burning.

Health care

- Look out for symptoms of illness, especially cough, fever, fast or difficult breathing, loss of appetite or poor weight gain, diarrhoea, and vomiting, and treat these or seek treatment as soon as possible.

Make sure the child is immunised (but not with live vaccines if he or she has symptomatic HIV, see page 37).

Avoid common infections, for example by keeping a child away from others who have pneumonia, tuberculosis and measles. Young children should not, if possible, sleep in the same room as an adult suspected of having TB disease.

Parents can help protect a child against malaria by making sure he or she sleeps under a bednet, preferably one impregnated with insecticide, by using coils and repellents to keep mosquitoes out of the home, and by draining pools of water that may be mosquito breeding areas.

Check the mouth for sores and thrush and treat these promptly.

Nutrition and general care

Give regular nutritious food to help the child grow and fight off infections.

Make sure the child gets enough sleep and rest.

Treat the child like other children. Children with HIV are not sick all the time and should lead as normal a life as possible, including playing with other children.

Nutrition and children with HIV and AIDS

Children with HIV often lose weight or fail to thrive and grow. Repeated episodes of diarrhoea and other infections often result in loss of appetite and further weight loss. Special efforts are needed to make sure that they do not become severely malnourished.

WHO

Regular nutritious food helps the child grow and fight infections.

Malnourished children are more vulnerable to infection and the problem is made worse in those with HIV who are already at greater risk of infection.

It is therefore very important that children with HIV eat a good diet, to help them resist and fight off infections. They particularly need to get enough vitamin A in their diet because it helps to protect against diarrhoea and respiratory infections. A good diet includes:

Energy-rich foods such as maize, rice, millet porridge, bread, cassava, plantain or yam. These provide the main part of the meal and most of the energy. Sugar, animal fats, coconuts, nuts and vegetable oil are a concentrated source of energy.

Body-building foods such as meat, chicken, fish, eggs, dairy produce, nuts and beans. These foods contain protein and micronutrients such as iron, zinc, calcium and some vitamins.

Vitamin-rich foods such as dark green leafy vegetables and orange and yellow fruits.

Family foods can be made more nutritious and easy to eat. For example, porridge can be made more energy-rich by adding vegetable oil or nuts or adding mashed pulses, vegetables, milk, fruit juice or coconut milk. Fermenting or malting can make foods such as porridge more nutritious and easier to swallow.

Feeding and illness

Children who are sick often lose their appetite. They need to be encouraged to eat small meals more frequently than usual, made with foods they like. Giving lemon juice in warm water or ginger drink can help reduce nausea. Unsweetened yoghurt and fermented foods like sour porridge are good for candida (oral thrush).

Children with diarrhoea should be given well cooked local staples that can be easily digested in a soft mashed form and with added energy. Rice, barley, bananas and sweet potatoes are good staples. Foods rich in potassium, such as spinach, bananas, coconut water, avocado, should be given to replace potassium losses during diarrhoea. Refined, canned or junk foods should be avoided because they are less nutritious. Steaming or stir frying are good cooking methods because they do not remove as much of the nutrients from food as other methods. Spicy or fatty foods should also be avoided as these can worsen nausea.

After illness it is important that children eat more to help them recover and build up their strength. A simple rule is to give an extra meal a day until the child has reached the same weight as before the illness.

C Stauffer/WHO

Clean food preparation and storage can reduce the risk of infections.

Safe preparation of food

Clean food preparation and storage can reduce the risk of infections, especially diarrhoea.

Food should be cooked until it is thoroughly heated and bubbles. Cooked food should not be stored for more than 24 hours and any food that has been kept for more than two hours should be thoroughly reheated. Food and water should be stored in clean covered containers.

Boiled and cooled water should be used to wash fruits and vegetables, and for cooking and drinking.

Wash hands with soap and water before preparing and cooking food or feeding a child.

Taking care of common conditions

Fever

- A child has fever if he or she has a high body temperature (above 37.5°C).
- Remove unnecessary clothing and blankets.
- Put the child in the fresh air, preferably where there is a breeze.
- Make sure the child drinks plenty of fluids because fever can make him or her dehydrated.
- If the child has high fever (more than 38.5°C), give paracetamol to reduce the fever.
- The child should be taken to a health centre if the fever continues for more than three days. If the child also has a cough and is losing weight, has a stiff neck, severe pain or sudden diarrhoea or convulsions, or there is malaria in the area, he or she should be brought sooner.

Diarrhoea

- A child has diarrhoea if he or she passes more than three loose stools in a day.
- Diarrhoea can cause dehydration because of the loss of fluids and body salts.
- Dehydration is dangerous in infants and small children.
- Treating diarrhoea at home involves three important actions: giving the child more fluids to drink than usual, continuing to feed the child, and seeking care when needed.
- Parents should bring the child to a health centre if there is blood in the stools, if after three days there are still many watery stools, if the child vomits repeatedly, eats or drinks poorly, has fever, or is very thirsty.
- Additional fluids should be safe and include, as well as plain water, those which contain salt, such as ORS, salted soup, such as carrot soup, salted rice water.
- Other good home drinks for children with diarrhoea are green coconut water, yoghurt drinks, unsweetened tea, unsweetened fresh fruit juice, and water in which a cereal such as rice has been cooked.
- Medicines are not necessary for most children with diarrhoea.

Skin problems

- Skin problems include rashes, itching, painful sores and abscesses.

How to give oral rehydration salts (ORS) solution

- A cup is the best method because it allows the fluid to be given in small steady amounts which reduces vomiting. About one teaspoon every two or three minutes is a useful guide.
- Older children can drink on their own from a cup.
- Plastic droppers are more difficult to keep clean and free of germs.
- Carers need to be patient and persistent when giving ORS. If a child refuses to take any more fluid after a time, it usually means that he or she has had enough.
- A child under two years needs about 50–100ml (between a quarter and half a cup) of fluid after each loose stool.
- Older children require about 100–200ml (half to one cup) of fluid after each loose stool.

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Cleaning the skin with soap and water and keeping it dry between washing can prevent most common skin problems. Salty water can be used as a disinfectant.

Carers should try to stop young children from scratching if possible as this can cause infection. Keeping the nails short and clean helps. Carers can also try putting gloves over the child's hands.

The irritation and itching can be reduced by cooling the skin with water or by fanning it, by applying calamine lotion and by not letting the child get too hot.

If the skin is very dry, washing with soap and water can make it worse. Oils or creams, such as vaseline, glycerine or vegetable or plant oil (for example, coconut oil) can be used instead.

Avoid perfumed oils, soap and lotion as these may irritate the skin.

Children in nappies and those with diarrhoea need careful skin care. To prevent sores and rashes, leave the baby's bottom exposed to the air as much as possible, wash the baby's bottom between nappy changes with warm water, and use a barrier cream such as zinc and castor oil. Leaving the baby in wet nappies or cloths causes rashes and sores.

- Potassium permanganate solution makes a good antiseptic for soaking infected sores. Add a pinch of crystals to a litre of clean water.

Shingles

Shingles begins as a painful rash with blisters and healing takes several weeks.

Apply calamine lotion twice a day to relieve pain and itching, and promote healing.

- Keep sores dry and relieve pain with paracetamol.

Bathe in salt water or apply gentian violet to prevent infection.

Bed sores

Children may get sores if they are very weak and stay in bed a lot of the time.

The sores form on bony parts of the body.

Carers should try to encourage children to get out of bed or move them around and change their position if they cannot crawl or walk.

Soft bed sheets or padding that are well aired can help to prevent sores, as can making sure the bedding is not wrinkled.

Bedding should be changed after it has been soiled with urine or faeces.

How to make gentian violet solution

To make a 0.5% solution

1. Put one level 5ml spoonful (approximately 5g) of gentian violet crystals into one litre of clean water.
2. Stir well and leave to settle.
3. Filter the solution through material or gauze, or carefully pour the solution into another bottle, to remove any particles of undissolved gentian violet crystals. If left in the solution, they may cause skin irritation.

To make 0.25% solution

Mix equal parts of 0.5% gentian violet solution and water. For example, mix 50ml gentian violet solution with 50ml water.

Note: Do not keep gentian violet solution for longer than seven days.

Mouth and throat problems

Mouth and throat problems in babies with HIV are usually caused by thrush (white patches) or herpes (painful blisters on the lips).

- A sore mouth or throat problem can prevent a baby from eating and drinking properly, as well as making him or her irritable and feverish.

Carers can help reduce the problem by rinsing the baby's mouth out with salt water (half a teaspoon of salt in a cupful of clean water) after eating and between meals. If the child is old enough, encourage him or her to swish the salty water around the mouth and to spit it out. If not, use a clean cloth or cotton wick soaked in salt water. If possible, clean the mouth at least four times a day.

- Liquids such as soups, fruit juices and yoghurt are good when a child has a sore mouth. Liquids can be taken more easily with a straw.
- Cold foods and drinks may relieve discomfort. Spicy or salty foods and citrus fruits like oranges should be avoided as these can irritate sores.

Soft foods are easier for babies to chew and swallow if they have a sore mouth or throat.

- If the baby has thrush, the tongue and inside of the mouth should be gently brushed with a soft toothbrush several times a day, and rinsed with salty water.
- Applying 0.25% gentian violet solution (see box) three or four times a day can help treat thrush and herpes blisters.

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Giving medicines to children

- Liquid medicines can be squirted slowly into the side of the child's mouth using a dropper or syringe or poured from a spoon.
- Always praise the child after he or she has taken the medicine.
- If the medicine tastes bad, tell the child in advance.
- If a pill cannot be swallowed, crush it and mix it with the smallest possible amount of milk or food or sugar. Do not hide medicines in food or the child may start to refuse to eat.
- If the child vomits immediately after taking the medicine, give the dose again. If vomiting happens more than 20 minutes after taking the medicine there is no need to give the dose again.

Respiratory problems

- A blocked nose can interfere with a child's eating and drinking.
- Carers should clear the nose if it is congested. Dry or sticky mucus can be softened and removed using a cotton cloth wick moistened in clean salt water.
- Children with respiratory illnesses can get dehydrated. They should be given more to drink than usual. This will also help their cough and soothe a sore throat.

Parents should bring the child to a health centre immediately if he or she shows signs of difficulty in breathing, wheezing, breathes faster than usual, or cannot drink because of breathing problems.

- Sitting up a child or raising his or her head on pillows can help a child with a constant cough or breathing problems.

Pain control

- Carers can help to relieve pain in young children with paracetamol (which is safer for children than aspirin).

Give babies aged less than six months, one eighth of a tablet (62mg) two or three times a day (or every eight hours).

Give children aged six months to two years a quarter of a tablet (125mg) two or three times a day.

Children aged three to seven years should be given half a tablet (250mg) two or three times a day.

Management of common infections at primary care level

Pneumonia

The most common causes of pneumonia in children with HIV are the same as in those without HIV. Diagnosis and management is therefore the same: signs of fast breathing, cough and chest indrawing are used for diagnosis; treatment uses standard out-patient antibiotics.

However, recurrent pneumonia is more common in children with HIV, pneumonias may be more severe and bacteraemia is more common in these children.

Children with severe pneumonia or very severe disease, should be given a first dose of antibiotic before urgent referral to hospital. Children who fail to respond to standard treatment or who have cough for more than 30 days should also be referred. HIV-infected children are also more likely to have PCP for which prolonged, higher dose cotrimoxazole treatment is required (four times a day, double the normal dose). However, this treatment decision will usually be made at the hospital to which a child is referred.

Oral thrush and herpes zoster

Oral thrush (candidiasis) or herpes zoster should be treated with half strength (0.5%) gentian violet for 3–4 days. The mother or other carer should be advised to return for follow up.

If the condition is improving, continue with gentian violet treatment until it is better. If oral thrush has not improved:

- apply miconazole gel to affected areas at least 3 times daily for 5 days OR
- give 1ml nystatin suspension (100,000 IU/ml) 4 times daily for 7 days, pouring slowly into the corner of the mouth so that it reaches the affected parts.

The presence of pus may indicate a secondary bacterial infection. Apply tetracycline or chloramphenicol ointments. If there is a foul smell in the mouth, use metronidazole suspension (<3 years old: 50mg 3 times a day; older children: 100mg 3 times a day).

Nystatin is a more expensive drug and its use should be limited to treatment failures with gentian violet.

If the child has problems swallowing or cries when swallowing, has repeated vomiting, or has problems feeding, refer to hospital for alternative treatment.

Tuberculosis

HIV infection increases a child's susceptibility to tuberculosis (TB) infection and is an important cause of progression of TB infection

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Recurrent pneumonia is more common in children with HIV.

to TB disease. The case fatality rate associated with TB is higher in HIV-infected children. This is partly due to TB itself and partly due to other HIV-related problems. In areas where HIV infection is prevalent, it is important to consider whether or not a child has TB. The possibility of tuberculosis, pulmonary and extra-pulmonary, should always be considered in a child with HIV.

The diagnosis of TB in children with HIV is difficult. Early in HIV infection, when immunity is good, the signs of TB are similar to those in a child without HIV infection. But, in some children with HIV and TB, the symptoms of TB may be different, for example fever without cough or swollen glands in the neck.

If HIV is more advanced, TB can spread to other parts of the body and progress to serious disease more rapidly. Disseminated disease, tuberculous meningitis and enlargement of the lymph nodes are more common in children with HIV.

A child with cough for more than one month, recurrent fever, poor weight gain or weight loss should be suspected to have TB and treated. Children with HIV infection who have tuberculosis will usually respond to standard TB treatment.

Standard TB treatment is based on an initial intensive phase where two or three drugs are given daily for two months, followed by a continuation phase for four or six months. Health workers should follow national TB treatment policy guidelines.

To cure TB it is essential that the right dosage is taken regularly under supervision for the whole of the treatment period. Health workers need to follow up carefully to ensure that children are being given TB treatment correctly.

NOTE: Children with HIV should NEVER be treated for TB with thiacetazone because this drug can cause severe and sometimes fatal side effects in patients with HIV. Thiacetazone is associated with a high risk of severe, and sometimes fatal, skin reactions in HIV-infected children. These reactions can start with itching skin but progress to more severe reactions where the skin peels off. For this reason, in areas where HIV infection is common, the best treatment regimens are those based on rifampicin, isoniazid and pyrazinamide.

It is also important to check the TB status of the child's parents. Studies have shown that TB is transmitted from TB-infected parents to children, and children with HIV are particularly at risk.

Persistent or bloody diarrhoea

Persistent diarrhoea (diarrhoea which goes on for more than 14 days) is more common in children with HIV. The most important treatment for all children with persistent diarrhoea is oral rehydration therapy and proper nutritional management including a modified diet and giving extra vitamins and supplements.

Nutritional management can include temporarily replacing animal milk with fermented milk products such as yoghurt or replacing half the milk with complementary foods. In some places where lactose intolerance is not considered to be a problem, such as Zimbabwe, cow's milk is not replaced.

If the diarrhoea continues or the child is severely dehydrated, he or she should be referred to hospital.

Bloody diarrhoea is usually caused by shigella and health workers should treat with a drug that is effective against shigella, according to local guidelines. Referral to hospital is required if there is no improvement after two days of treatment for bloody diarrhoea.

Malnutrition
Malnutrition is one of the most important causes of illness and death in young children with HIV and AIDS. Repeated infections, especially diarrhoea, worsen a child's nutritional status. It is very important that mothers are given practical advice about feeding, including during and after illness, to prevent malnutrition. Although nutritious food is the best source of vitamins and minerals, an HIV-positive child with poor nutrition may benefit from being given vitamin and mineral supplements. Tablets are best for children. Injections are painful, expensive, rarely necessary and can cause abscesses.

Measles
Measles can be more severe in children with HIV. Children with HIV infection who get measles are more likely to die than children without HIV.

All children should receive measles immunisation. It is especially important that infants with HIV are vaccinated against measles.

Fever
Children with HIV who have fever (feels hot, fever reported by the mother or axillary temperature above 37.5°C) should be checked for malaria and measles and treated if required. They should also be checked to see if they have serious bacterial infection and treated with antibiotics as necessary.

A single dose of paracetamol should be given to children with high fever (axillary temperature of 38.5°C or above, rectal temperature 39°C or above).

Malaria
Children with HIV who have simple malaria can be treated as out-patients in the same way as children without HIV. Children who have severe and complicated (cerebral) malaria should be referred as medical emergencies.

Otitis media
Chronic ear infections are more common in children with HIV, but management of acute and chronic otitis media is the same in all children regardless of HIV status. However, children with HIV need to be monitored carefully because they are at greater risk of developing mastoiditis and may need to be referred for hospital treatment.

Clinical follow-up

Health workers should ensure that the following issues are monitored during regular clinic visits for children with HIV or those suspected to have HIV:

- **clinical condition**
- **immunisation**
- **growth and nutrition**
- **psychosocial support.**

Pneumocystic carinii pneumonia
High dose cotrimoxazole (trimethoprim (TMP) 20 mg/kg/day, sulphamethoxazole (SMX) 100 mg/kg/day in four divided daily dosage, IV if possible or orally) should be initiated promptly and continued for 21 days. If therapy cannot be completed due to severe drug reactions, pentamidine, where available, can be given as a substitute (4mg/kg/day by IV infusion for 21 days).

Oesophageal candidiasis
Give ketoconazole (3–6 mg/kg/day) for 7 days except if the child has active liver disease. Amphotericin B (0.5mg/kg/day by IV infusion for 10–14 days) should be considered in cases of:

- lack of response to oral therapy
- inability to tolerate medications
- risk of disseminated candidiasis (for example, a child with leucopenia – a low level of white blood cells).

Lymphoid interstitial pneumonitis
Treatment should be initiated only if there are signs of severe hypoxaemia (dyspnoea, fast breathing, cyanosis, finger clubbing) and it is possible to complete full treatment. Treatment is with corticosteroid (prednisone 1–2 mg/kg/day) orally. The dosage and duration of treatment is dependent on the clinical response confirmed by x-ray. As treatment may last a long time, close monitoring for side effects of the steroid is important. Note that steroids are immunosuppressants and may increase the risk of TB and opportunistic infections in HIV-positive children. The likely benefits of treatment must be weighed against these potential adverse effects. Other causes of interstitial pneumonia should be ruled out before starting corticosteroid treatment because of the potential adverse consequences of this treatment in immunocompromised children.

Referral and treatment

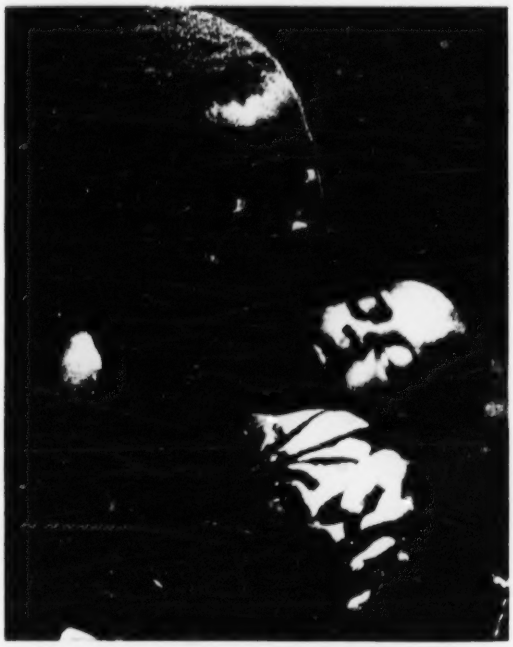
Children may require referral for: HIV testing with pre- and post-test counselling, if these are not available at the first level; to another centre or hospital for further investigation if there has been poor response to the usual treatment; or to a community or home care programme for counselling and further support.

In most settings, it should be possible to treat common infections in children with HIV at the primary care level. Referral decisions will depend on the availability of referral level care and treatment for children with symptomatic HIV infection and AIDS.

Children who should be referred include those who are:

- not responding to treatment (treatment failures)
- suffering from recurrent serious infections
- sick and under the age of two months.

Children who do not respond to standard treatment may have opportunistic infections such as PCP or cytomegalovirus. Very young infants who are sick are very vulnerable and



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Children may need to be referred if there has been a poor response to the usual treatment.

Immunisation: protecting against common childhood infections

Children with HIV and AIDS are vulnerable to childhood infectious diseases and need the protection provided by immunisation.

Follow standard immunisation schedules for children with HIV with these exceptions: do not give BCG vaccine or yellow fever vaccine to HIV-positive children who are *symptomatic*.

Children who have, or are suspected to have, HIV infection but are *not symptomatic* should be given all vaccines, including BCG and yellow fever.

All children with HIV and AIDS should therefore receive DPT (diphtheria, pertussis, tetanus), measles and polio (killed polio) vaccines. This applies even if they are sick.

Children with HIV disease or symptoms of AIDS should not be given BCG vaccine because BCG vaccine has very occasionally caused complications or disseminated BCG disease (illness caused by the vaccine itself) in children with severe immunodeficiency. Yellow fever vaccine is also contraindicated in children who have symptomatic HIV infection or AIDS because there is a risk of severe reaction.

However, in most countries, BCG vaccine is given soon after birth, before any symptoms of HIV or AIDS appear. Where this is standard practice, all infants should receive BCG vaccine because it helps to reduce the more severe complications of tuberculosis meningitis and disseminated disease in childhood.

Children with HIV seem to be more vulnerable to death from measles before the age of nine months (the time when measles immunisation is usually given). If health workers know that the infant has HIV infection, they could consider giving a dose of measles vaccine at six months of age as well as at nine months. However, this should only be done if it is consistent with national immunisation policy.

In countries where other vaccines such as *Haemophilus influenzae* type b or pneumococcal vaccine are included in routine childhood immunisation schedules, these vaccines should be given regardless of the HIV status of the child. Hepatitis B vaccine can also be given to all children regardless of their HIV status.

Immunisation of infants and children with HIV and AIDS

Vaccine	*Asymptomatic*	*Symptomatic*
BCG	Yes	No
DPT	Yes	Yes
OPV	Yes	Yes
Measles	Yes	Yes
IPV	Yes	Yes
Yellow fever	Yes	No

need to be given special care in hospital.

The reason for referral should always be discussed with the mother or caretaker. The referral note should be clear and comprehensive while maintaining confidentiality.

For more information about diagnosis, management and referral of more severe illness refer to the WHO guidelines on Integrated Management of Childhood Illness.

Palliative care in terminal HIV/AIDS

If a child gets very sick with AIDS when little can be done to enable him or her to live longer, the decision to stop trying to prolong life must be made by the parents or other carers. After this, terminal or palliative care (alleviating symptoms but not trying to treat the underlying condition) is given.

Every health worker needs to be prepared to deal with a child with terminal HIV / AIDS. The decision to give palliative care should only be made if:

- the child has a progressively worsening illness; and
- everything possible has been done to treat the presenting illness.

Palliative care means helping the dying child to be as comfortable as possible, even where resources are limited. One important decision to be made is where the child will die, for example at home, or in a health facility. If at home, health workers need to provide carers with support, advice and appropriate drugs. Health workers can also help to mobilise support from the family and community to reduce pressures on the immediate carers.

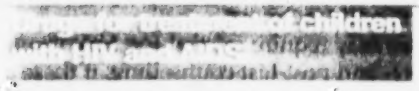
Even when the prognosis for a child is poor, pain control and relief of distressing conditions, such as oesophageal candidiasis or convulsions, can significantly improve the quality of a child's remaining life. An HIV-infected child is often uncomfortable in the terminal stages of life due to a number of conditions, described below. Good palliative care is essential in these circumstances.

Pain control

The management of pain in HIV-positive children follows the same principles as other chronic diseases (such as cancer or sickle cell disease). Attention must be paid to ensure that care for pain is culturally appropriate and sensitive.

In children with HIV / AIDS, pain may be related to the disease itself, associated infections or procedures used in diagnosis and treatment. Painkillers should be given before the pain gets very bad and regularly while it lasts. The following drugs can be used in the effective management of pain in the terminal stages of illness.

Local anaesthetics – should always be used for painful procedures, skin lesions or mucositis. Lidocaine, an injectable local anaesthetic works in 2–5 minutes. TAC (tetracaine, adrenaline, cocaine) can be placed on a gauze pad and placed over open wounds.



Antiretrovirals

In richer countries, HIV-positive children are treated with antiretroviral drugs. These drugs seem to improve quality of life but it is not clear whether they prolong life.

But, as explained earlier, antiretroviral drugs are very expensive. One side effect is anaemia which means that patients need frequent blood transfusions. Patients given antiretrovirals also need to be carefully monitored.

Prophylactic treatment

Prophylactic treatment with cotrimoxazole (TMP 10mg/kg/day, SMX 50mg/kg/day in 2 daily dosages for 3 days a week) has been shown to reduce the incidence of PCP and bacterial infection in HIV-positive children. WHO recommends cotrimoxazole as the drug of choice for prophylaxis of children with recurrent serious infections, because it is sensitive to many bacteria and protozoa, is low cost and widely available. However, the availability of drugs, the costs of prophylaxis and the possibility of development of cotrimoxazole resistance also need to be considered. In addition, the most severe cases tend to develop in infants aged less than six months when it is difficult to know their HIV status. This makes decisions about when to start prophylaxis difficult. Prophylactic treatment in children with HIV infection for PCP must be consistent with national treatment policies and guidelines.

Basic drugs

In many countries, even basic drugs for treatment of common infections in children, including first and second line antibiotics, are not available. Making these available – and drugs for treating tuberculosis and antifungal drugs for thrush – must be the first priority for health services. In addition, more efforts must be focused on ensuring that drugs required when standard treatment fails and palliative drugs for end of life care are accessible where they are needed.

Non-opioids – appropriate for mild and moderate pain. Paracetamol 10–15 mg/kg orally 4–6 times daily. Aspirin can be used as an alternative to paracetamol in terminal stages of illness.

Opioids – appropriate for moderate and severe pain not responding to treatment with paracetamol or aspirin. Children need to be monitored carefully for side effects, which are common, the risk of respiratory depression, and the possibility of tolerance and dependence. In infants under six months of age, the initial opioid dose should be a quarter of the dose given to older children. Doses should also be reduced for children with severe malnutrition, liver and kidney problems and multi-organ system failure.

- Morphine is well studied, inexpensive and is a strong opioid. It may be used orally (0.2–0.5mg/kg/dose every 4–6 hours), IV (0.05–0.1mg/kg/dose every 4–6 hours) or by continuous infusion (0.005–0.01mg/kg/hr).
- Codeine – combined with non-opioids to give additional pain relief (0.5–1mg/kg/dose every 6–12 hours).

Anorexia, nausea and vomiting

There are no easy solutions to loss of appetite in terminal illness. Caregivers should be encouraged to continue giving the child regular meals. Nasogastric feeding may be necessary and, if appropriate, caregivers should be shown how to do this. Oral or IV rehydration may be necessary, as may the use of anti-emetics such as metoclopramide (1–2 mg/kg/dose every 2–4 hours) in very distressing nausea and vomiting.

Pressure sores

Caregivers should be shown how to turn the child at least once every two hours. If pressure sores develop they should be kept clean and dry. Local anaesthetics such as TAC can be used to relieve pain.

Care of the mouth

Caregivers should be taught how to clean the mouth after every meal. If mouth ulcers develop, clean the mouth at least four times a day using clean water or salt solution and a clean cloth rolled into a wick. Apply 0.25% gentian violet to the sores. Give paracetamol if the child is feverish, irritable or in pain. If the child is bottle-fed, recommend that a cup be used instead.

Airway management

Airway management is particularly important when the child is unconscious. In these cases, the child ideally should be in a hospital or hospice where trained staff can manage the airway. Where the parents wish to have the child dying at home, it will be necessary to train them to nurse an unconscious child and to keep the airway clear. A manual suction device can be used and parents taught how to use it. Many terminal patients develop respiratory distress as they near death.

3.8 Affected children

KEY POINTS

- It is often better for children who have lost one or both parents because of AIDS to remain in their own community and be cared for by other family or community members.
- Helping families and communities cope with young children who are affected by HIV and AIDS is a key role for health workers.

Children who are not infected with HIV may be affected by HIV and AIDS. Those who have lost their mother, father or both parents have to deal with loss and grief, face stigma and discrimination, and their physical and emotional health may be affected.

It is better in most cases for children to stay in their own community. There have always been orphans in all societies and it is important to investigate locally how a culture responds to orphans. Children may be looked after by grandparents, older siblings, aunts or other relatives.

But in many places, the additional responsibility of taking care of children affected by HIV and AIDS is placing great strain on the extended family and on community resources. Families that are already poor or who have lost income from wages or agriculture because of the death or illness of wage earners are finding it difficult to cope with looking after additional children. Those that have already spent money on treatment and funeral expenses for the parents may be reluctant to take care of children who are left. Toddlers and babies may also be considered to be a burden because they need more care and cannot contribute to family income.

An older brother who is looking after his younger siblings describes what happened to them: 'my aunts and paternal grandmother refused to take care of us. The matter was reported to the police who assessed the

situation and gave custody of the children to me.'

Households headed by older children are especially vulnerable. Their problems include:

- poverty
- lack of supervision and care
- stunting and hunger
- educational failure
- lack of adequate medical care
- psychological problems
- disruption of normal childhood and adolescence
- exploitation
- early marriage
- discrimination
- poor housing
- child labour.

Young children looked after by other caregivers, such as grandparents or older siblings may have worse health and nutrition. This is because substitute caregivers may:

- have less knowledge about how to manage childhood illness, about good nutrition or about immunisation
- have less knowledge than mothers about recognition of illness in sick children. Older siblings, aunts or grandparents who are looking after a large number of young children may be unable to pay for food or travel to clinics, or may have insufficient time to care for young children when they are sick
- assume that children whose parents have died are themselves infected with HIV. Because of this, they may be denied health care by health workers, or families may be reluctant to spend time and money on treatment when they are sick.

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Households headed by older children are especially vulnerable.

Children who have lost a parent or both parents may be confused and unhappy if they have moved away from their home to live with relatives they do not know well and are separated from their brothers and sisters. A lack of love and care can affect children psychologically. Although children whose parents have died because of AIDS are often described as 'innocent victims', they may be neglected, rejected or stigmatised by others in the community or by those who are now looking after them. These children need emotional and psychological support, and those caring for them need support to enable them to deal with their needs.

What can health workers do?

Health workers in some countries are increasingly having to deal with infants and children with no mother who are cared for by grandparents or older siblings. Health workers need to make sure that these children receive health care for common illnesses in the same way as other children and that they are immunised, and to monitor their nutritional status carefully.

It is important to ensure that grandparents and children who are themselves caring for young children receive education and information about primary health care.

Health and community workers can also ensure that caregivers are provided with information about managing illness and about nutrition that is relevant to their circumstances. They can help caregivers to identify their needs in terms of material and emotional support and help them to obtain assistance.

Practical support from the community or from community care programmes should also be considered to help children affected by AIDS. These children must not be singled out and support should be directed towards families and communities, especially child-headed households.

Working with communities takes time and longer term support is better than intensive short term 'relief'. It is also better to support existing community coping mechanisms. This

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Identifying the main caregivers and community coping mechanisms is an important first step.

means finding out what people are already doing and what structures, such as churches and schools, are already there, rather than introducing new initiatives from outside which may not be sustainable.

The first step is to identify who the main caregivers are and what infrastructure is available to provide support. Ways to help families and communities to cope could include:

- providing counselling services to counsel the family or caregivers, psychological, spiritual and social support
- providing economic support, or encouraging support from the extended family and other community members
- encouraging greater involvement of men in the care of young children
- mobilising community groups, churches, religious, political and traditional leaders
- arranging for temporary support and care for families during particularly difficult times, for example when a child (or a parent) is very sick
- identifying referral and social services
- supporting measures to reduce stigma and discrimination
- training community volunteers in counselling skills so that they can support families
- regular visits to support home-based care and to monitor how well families are coping.

Strategies and coping mechanisms for child-headed households in particular could include:

- temporary or permanent fostering
- relocation to an adult relative's family
- adult relative moves in with children
- regular supervisory and support visits from family or community members
- material support from relatives
- assistance with care of younger siblings.

Community leaders as well as community and health workers can play an important role in encouraging relatives to fulfil family responsibilities, and in protecting the rights of widows and children to land and inheritance. As one home care volunteer in Zimbabwe noted: 'The late husband's family take everything, but sometimes the community elders intervene'.

Health and community workers can counteract stigma and rejection, by making sure that people understand how HIV is and is not transmitted. The FOCUS visiting programme, described in the box on the following page, not only contributed to the welfare of children but encouraged a more human attitude towards orphans.

Child rights and HIV and AIDS

HIV is a child rights issue.

Although, under the UN Convention on the Rights of the Child, all children have the right to health care, education, social services, protection from discrimination, exploitation and abuse, and to survival and development, children with HIV or affected by AIDS are often denied these.

In most countries, young children who are orphaned have few legal or customary rights to family property or land. Few children have any say in what happens to them. Consideration needs to be given to children's rights in relation to inheritance and to deciding on their future.

Community-based support programmes

In Uganda

In Luwero District, one in five children under the age of 18 years has lost at least one parent. The most important needs are for school fees, food, bedding, clothing, and medical care.

Practical support for orphans and their carers, through AMREF and the Francois-Xavier Bagnoud Association, has included assistance to guardians with developing income-generating activities and support to schools to enable children to attend without paying fees.

In Zimbabwe

The Families, Orphans and Children Under Stress (FOCUS) programme in Mutare, Zimbabwe, is supported by the Family AIDS Caring Trust. The programme supports community-based orphan initiatives in four rural sites in Manicaland, through volunteers from local churches. In most cases the volunteers are women, many of them widows, who are provided with basic training so that they can identify and register orphans in the community.

Orphans in need of assistance are identified, regular visits are made, and material support is provided to enable children to stay in their homes and communities. In the last six months of 1996, the 88 volunteers made nearly 10,000 visits to over 3,000 orphans in 798 families. The most needy are visited the most regularly.

Practical help provided by volunteers has included helping children to rebuild their homes, food, blankets, and primary school fees. Projects have been started in all four sites to encourage self-reliance.

An important aspect has been identifying ways to support orphans that complement existing coping mechanisms, enabling them to be supported within their own communities. Also crucial has been encouraging the more important members of communities to be involved in helping affected families. This has in turn encouraged other members of the community to provide support and has been an important strategy for reducing stigma and community rejection. One family, with an older sister looking after several younger siblings, had been ignored by the community – 'we had no visitors because we are so poor we have nothing to give them' – until community leaders became involved in helping to repair the house. The family now receives support from neighbours.

Another project, the Elim Hospital Community-Based Orphan Support Programme, involved men as volunteers in home care and orphan support to share the burden with women.

Lessons learned from these programmes include:

- the importance of involving all members of the community
- only community-based organisations can implement these programmes
- the community and the catchment area where the programme will operate needs to be defined
- programmes are more likely to succeed if they are based on and develop pre-existing activities
- volunteers are the most important resource and care is needed in selecting, training, supporting and motivating them
- steps in client identification include defining the target group, enumeration, registration and needs assessment.

Problems associated with such programmes include:

- stigma attached to AIDS, so that it remains largely hidden
- the needs of children are often not prioritised because children rarely have a voice
- policy makers often still prioritise resource allocation to institutional responses rather than community-based responses.

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Strategies for dealing with children orphaned by HIV and AIDS

The following is a summary of the three approaches that have been most commonly used to support children orphaned by HIV/AIDS:

1. institutional
2. reactive
3. community-based.

1. Institutional
There are various types of institutional orphanages. These often provide high quality care in terms of material needs such as food or clothing. But they have limited capacity, are often expensive to run and do not meet other needs of children, such as belonging to a community. The institutional approach is generally not recommended because it is too costly and therefore unsustainable, and is generally seen as a temporary and last resort.

2. Reactive
Various organisations have reacted to orphans coming to them by providing for their basic needs. Again this approach mostly addresses physical needs. It may also not reach the most needy and encourages dependency.

3. Community-based
With this approach, community-based volunteers identify the most needy children within the community and visit them regularly. Material assistance, where it is provided, is channelled through the volunteers. Emphasis is placed on support to encourage self-reliance rather than dependence on ongoing external inputs.

The orphan policy developed by the Department of Social Welfare in Zimbabwe, clearly encourages community-based care as the best and most cost-effective method of caring for orphans, as the following (adapted from the draft Zimbabwean National Orphans Care Policy) illustrates.

Places for provision of child care (in descending order of preference):

1. immediate family
2. extended family
3. community support to elderly and adolescent headed households
4. foster care, adoption
5. village-type institutions
6. dormitory-type institutions.

Source: G Foster, FACT.

Issues for health workers

KEY POINTS

- Health workers face increased pressure and stress because of HIV / AIDS.
- Following recommended safety precautions can reduce the risk of transmission at work.
- Health workers need to consider how to talk to parents and children about HIV, and to help them plan for the future. Living positively with HIV should be emphasised for children as much as for adults.

This Section discusses strategies to address some of the important issues that health and community workers may be concerned about, including talking to caregivers about difficult subjects, lack of resources, stress and workload, and fears about their own safety.

4.1 Pressures on health workers

The increase in the number of women and children with HIV and AIDS is creating additional demands on health services and on health workers. Health workers face many pressures. These include:

- shortages of staff as colleagues become sick themselves because of HIV
- lack of skills or time to diagnose and manage children with HIV
- lack of resources for diagnosis and treatment including basic drugs for managing common infections
- higher numbers of children who require treatment and who fail to respond to standard treatment
- absence of services for referral for counselling, testing, treatment or community-based care

Sean Sprague / Panos Pictures

Heavy demands on health services add to the pressures on health workers.

IMC

Health workers need opportunities to share information and provide support to each other.

overcrowded hospitals

dealing with families' worries, fears and concerns and with death in young children on a daily basis

stigma because of working with mothers and children with HIV

fears about their own risk of HIV infection

powerlessness because of lack of knowledge and few available resources to do very much, and feeling that little is being achieved despite their best efforts.

All these contribute to health worker 'burn out' and may result variously in increased sickness, absence, early retirement, general stress and unhappiness at work. Health workers may feel sad, helpless, angry and tired. It is important for them to be able to talk to others about how they feel and to seek help when they need it.

Other steps need to be taken to reduce the pressure on health workers at national, district and primary or local levels.

At a national level, these steps could include:

- encouraging support for people with AIDS groups, with care and support as the main focus, and encouraging better integration of care and support activities with prevention activities
- developing clear policies and guidelines for diagnosis, treatment and care of children with HIV and AIDS
- promoting information dissemination, education and awareness-raising about HIV and AIDS in children
- continuing support for effective management of childhood illness
- emphasising prevention of infection in women by promoting safer sex, ensuring blood safety and avoiding unnecessary blood transfusions, and supporting effective STD control
- promoting children's rights and services for children, and models of care that encourage social integration and address discrimination
- implementing policies to ensure protection of children against sexual abuse and exploitation
- identifying interventions and therapies that work, and promoting them
- aiming for better discussion and knowledge of risks of infection at work and implementation of workable safety guidelines.

At district level:

- supporting community groups and home-based care programmes
- providing training and ongoing support for health workers
- establishing links with sectors outside the health service
- adapting guidelines to the local situation and making them available to health workers

Heldur Netocny/Panos Pictures

Careful handling of needles and other sharp instruments can reduce the risk of HIV transmission to health workers.

- involving members of the community (including people affected by HIV/AIDS) and primary health care workers in planning activities
- allocating resources carefully and planning services, especially providing essential drugs and supplies such as gloves
- developing systems to improve the continuum of care, referral and support for families providing home care, including encouraging links between district teams and NGOs.

At primary and community level:

- developing mechanisms for staff to share new information and provide support to each other, to help them talk about their problems and feelings, and to make their work more rewarding
- providing counselling services for health workers
- forming integrated home care networks involving community members, health workers and other service providers to improve care, provide mutual support and establish realistic expectations
- creating working links with NGOs, support groups, churches, and home and community care organisations
- developing training materials on home care and encouraging information sharing between support groups, community organisations, family members and health workers.

Preventing transmission in health facilities

Health personnel, especially nurses and midwives, are often worried about the risk of HIV infection at work. There have been reports of health workers refusing to deal with infants and young children with HIV and of laboratories refusing to handle specimens.

The risk of transmission from an infected child or mother to a health worker is very low if sensible precautions are taken, especially methods to reduce the risk of injuries from needles and other sharp instruments, and safe procedures for sterilisation, decontamination and handling specimens.

But even where it is not possible to follow recommended procedures, the risk of an infected mother transmitting HIV to a birth attendant or of an infected infant transmitting HIV to a health worker is still low. The risk of infection through needle-stick injury is estimated at 1 in 300.

There is a risk of HIV infection if health workers come into contact with blood or other body fluids through:

- open cuts or sores on their skin
- accidents such as needle pricks or blood splashes
- carelessness such as dangerously discarded needles or blades
- poor practices such as reuse of equipment without sterilisation or disinfection.

Factors increasing risk include:

- poor lighting
- emergency situations
- lack of gloves and other protective barriers

lack of disinfectants.

It is especially important to provide midwives, birth attendants and surgical staff with gloves and protective clothing as they may be at higher risk, because there is a large amount of blood at delivery and during operations.

Safety precautions

These precautions minimise the risk of transmission of HIV (as well as of hepatitis and other blood-borne diseases) and should be used when dealing with all patients regardless of their HIV status:

- careful handling, cleaning and disposal of sharps (needles, scalpels, blades), including properly placed puncture-resistant sharps disposal containers that are readily accessible, disposal of needles without recapping, without removing from the syringe and without breaking or bending by hand
- handwashing with soap before and after procedures
- using protective barriers such as gloves, gowns and eye masks to prevent direct contact with blood and other body fluids
- disposing safely of waste contaminated with blood and body fluids
- careful handling of soiled linen
- cleaning up spills of blood and body fluids with disinfectants
- covering broken skin, sores or cuts with a waterproof plaster or dressing before contact with patients. It is especially important that midwives and birth attendants cover insect bites, open wounds, sores and cuts on their hands and arms before attending a delivery.

In settings where resources are limited – for example, where gloves are in short supply – supplies should be used rationally. Gloves

[illegible] tuberculosis

Tuberculosis (TB) is spread as infectious particles through the air, either directly from person to person via coughing, or indirectly from dust on bedding, dressings, floors. For this reason, it is crucial to identify, isolate and treat people with TB to minimise risks to others. Proper ventilation, increased sunlight, and good working practices can also help to reduce the risk of infection.

The rise in clinic and hospital patients with HIV is mirrored by a rise in patients with TB. In many countries, one in three or one in two patients with HIV infection also have TB. These infections interact. Patients with pulmonary TB are infectious to others, especially to those with HIV. People who have a latent TB infection have a high chance of that infection being reactivated if they are also infected with HIV.

Health workers should take the following precautions:

- **isolating infectious patients**

  When a person is suspected of or diagnosed with TB, he or she should be isolated from other patients who do not have the disease. He or she should also be isolated from patients and staff known to have HIV infection during the initial phase of their treatment. Patients suspected of having TB who are known to be infected with HIV or to have AIDS should not be admitted to a TB ward until their TB treatment has been started.

- **making the environment safer**

  Accommodation for people with TB should be kept well ventilated with doors closed and windows to the outside open, to reduce the chance of airborne infection. Exhaust fans are useful for moving air from tuberculosis wards and isolation rooms to the outside. In colder climates it may be necessary to keep windows closed, but fans blowing air outside may be useful.

  Sunlight is a cheap source of ultraviolet light which kills airborne TB micro-organisms. If possible, patient rooms should have large, uncurtained windows.

- **safer working practices**

  Working methods should avoid creating dust which may contain TB micro-organisms. Carers should keep the patient's room aired and should avoid dry sweeping and shaking out soiled bedding and clothing indoors. Soiled bedding and clothing should be washed immediately using soap and hot water.

  Out-patient clinics where people are screened for TB should be well ventilated, and sputum specimens should be collected in an area away from general waiting rooms and other people.

  Infectious patients with uncontrolled cough should wear masks when being moved around the hospital or clinic. Alternatively, patients can use a clean handkerchief or cloth tied over their nose and mouth. Surgical or other masks will reduce infection risk from coughs and sneezes when worn by patients with pulmonary TB but are no help in stopping infection when worn by anyone else. For this reason it is not normally recommended that masks are worn by staff and visitors.

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should be kept for activities where there is the greatest risk of exposure, such as delivery, rather than for other procedures such as giving injections. Gloves should be changed between patients. If they are reused, only reuse intact gloves and wash and sterilise between uses.

If possible, health workers with open cuts and sores should avoid working where direct contact with patient's blood or body fluids is likely.

Risk of HIV and hepatitis transmission can also be reduced by eliminating unnecessary injections, episiotomies, and laboratory tests. In Uganda there is evidence that the main risk of occupational transmission is needle-stick injury to midwives performing stitching after episiotomies in conditions of poor lighting.

After delivery the placenta should be handled as little as possible and burned or buried.

It may also be possible for health workers to obtain more regular or additional supplies by finding out what is available through government and non-governmental sources, seeing if patients and their families can contribute, improving procurement, ordering and storage systems.

Care after exposure

If a health worker has been exposed to blood or body fluids through splashing, he or she should wash the area immediately with soap and water. Splashes to the eyes or mouth should be flushed clean with water or saline solution.

Wounds from needle-stick injuries should be cleaned with soap and water.

WHO recommends that incidents where health workers have been exposed to potentially infected blood and body fluids should be reported to the supervisor or manager, and that health workers be offered testing and counselling. In some countries, health workers are offered post-exposure prophylactic treatment with antiretroviral drugs, but this is not available in many places. There are also questions about the effectiveness of post-exposure prophylaxis.

4.3 Advising and counselling caregivers

Health workers play an important role in helping caregivers to cope when a child has HIV and AIDS and in helping to ensure that the needs of children affected by HIV and AIDS are considered. In addition to providing practical and emotional support to carers, specific issues which health workers may need to deal with include:

- emphasising the importance of living positively for children with HIV and AIDS as well as for adults
- helping parents to talk to a young child about HIV and AIDS
- talking to the mother and other members of the family about the fact that the child may die at a young age, and helping them to

Health workers can provide practical and emotional support to carers of children with HIV.

WHO

Children with HIV and AIDS should live as normal a life as possible.

come to terms with the death of a child or the fact that their child is dying

- discussing with parents who have HIV or AIDS what will happen to their children after they die.

Children living positively

Carers need to be aware that, with proper care, nutrition and treatment, young children can survive for several years and will not be sick all the time. Infants and young children with HIV and AIDS should live as normal a life as possible, participating in family and community activities and playing with other children.

Talking to children about HIV and AIDS

These basic guidelines may help when talking with young children.

Be honest in answering questions.

Tell the child enough but do not burden him or her with information about things he or she has no control over.

Bear in mind that young children have a different concept of time – to a young child two years is a very long time.

If you are telling a child he or she has HIV, you do not need to describe what it is in detail, but it is important to be honest about the fact that it may make the child sick from time to time.

Be prepared to answer questions such as: 'Will it hurt? Will I die?'

When children are close to someone who has AIDS or HIV, try to give them a message of concern and hope. When a parent is ill, the child's anxiety and concern will be much greater, but the message can continue in the same vein. 'Yes, Daddy is sick but he is doing all he can to keep himself strong and healthy and right now, things seem to be okay.' If the disease progresses and the person is obviously becoming more ill, it is appropriate to discuss this openly with the child. 'We are still hoping Daddy will feel better soon, but he may not. What do you think about that?'

It may be helpful to discuss ideas about death and dying in general, outside the

Confidentiality and children

Confidentiality is a difficult issue in relation to children.

The mother or parents have to decide whether or not anyone else is told that the child has HIV and who to tell. What she or they decide to do will depend on circumstances. Telling others, such as relations and neighbours, may have benefits such as extra help and support. But it could also place the parents and the child at risk of stigma, rejection and discrimination.

If the child's mother or both parents have died and the child is being cared for by another relative, should the carer be told that the child has HIV? Should the grandmother who is caring for a child with HIV be told of the child's status if the mother is alive at home?

Crispin Hughes/Panos Pictures

Support of friends or neighbours can help mothers to cope with the illness and death of a young child.

context of the sick individual. The possibility of the person's death should also be discussed frankly with the child.

Suggested steps in answering children's questions:

1. Listen carefully to the question.
2. If the meaning behind the question is not clear, or to better understand what the child is trying to ask, you could say, 'I wonder where you heard about that?' or 'Do you have any ideas what the answer might be?' This may give you more information to help answer the question.
3. Give simple, concise answers. Complicated words and lengthy replies may not be understood or the child may stop listening.
4. Check to see if the child understands.

Dealing with illness and death in a young child

Talking to the mother

Telling a mother that her child will die or is dying is probably one of the most difficult things a health worker or counsellor will ever have to do. There is no easy or right way to do this, and it needs to be handled very sensitively and gently. In most cases, telling a mother that her child has HIV also implies that she herself is infected.

It may help to think about the following issues.

- Where are you going to tell her? The place should be quiet and private and somewhere where she will be able to talk about her feelings comfortably. You also need to make sure that you allow enough time for her.
- How are you going to tell her? What words will you use? What is her situation? How do people in your culture feel about the death of a child? How will you bring the subject up? You could start by asking her how well (or ill) she thinks the child is and what concerns and worries she has about him or her. In cultures where talking about anticipated death is taboo, a health worker could instead say 'your child is likely to keep getting illnesses and each illness is likely to be more serious than the one before'.
- What might her emotions and feelings be? This can prepare you to talk to her about them. She may, for example, feel guilty if she thinks she is to blame. She may be sick herself and her child may have been her main reason for living.
- What support does she have available? Can she talk about it with her partner, parents, friends or neighbours? Or are they unaware of the baby's HIV infection? She may experience feelings of great sadness, hopelessness and despair. Who can she discuss her feelings with? Make sure she knows she can come back and talk to you again. She will be in shock and will need time to think. She may want to come back and talk about her feelings and any worries and questions later.
- How can she tell others? The mother may or may not decide to tell her partner, older children or other relatives about the baby's illness, but she needs to be helped to

consider whether this is wise and how she will do it.

What suggestions can you make to help her? Can you put her in contact with other women in the same situation? Are there any support groups for women and mothers? Is there a community care and support programme she can be helped by?

What practical concerns or questions might she have? This can prepare you to answer them. For example, she may want to know how long her child will live, whether he or she will be in pain, what she can do to make things easier for the child, whether he or she will need to go to hospital. She may be worried about hospital or funeral expenses.

Looking after a child who is dying is stressful and upsetting and adds to the burden of household work for women. Counselling can help them to cope and to solve problems such as identifying someone else to provide practical support.

When death is near, the family of the child will need emotional support, especially if they find it difficult to accept what is happening.

Health and community workers can offer and provide support to families, listening to them, helping to share their grief and giving comfort, as well as providing practical help. Unless invited to stay and help, the health worker should leave the family to mourn the child according to their cultural tradition.

After the child has died, families should take the same precautions when handling the body and with funeral arrangements as they did when the child was alive. These precautions include covering open wounds and sores, especially when handling, laying

Dealing with children's questions

Here are some ideas about answering children's questions which you could adapt.

Does AIDS hurt?
Most people with AIDS feel sick a lot of the time. Some people with AIDS feel okay. AIDS hurts during the times people with AIDS feel sick.

Does HIV infection hurt?
Some people with HIV feel fine. Some people with HIV feel sick. HIV hurts when people who have it feel sick.

Can doctors make people with AIDS better?
Sometimes doctors can help people with AIDS feel better, but no one knows how to get the germs out of the body once they have got it.

How long are people sick with AIDS?
People with AIDS will probably be sick their whole lives. AIDS doesn't go away the way a cold does.

Do people get AIDS from being bad? (Are people with AIDS being punished for doing bad things?) Do bad people get AIDS?
No. AIDS is caused by a germ. People get AIDS because the AIDS germ got into their body somehow. All kinds of people get AIDS. Getting AIDS doesn't have anything to do with whether someone is good or bad. Germs don't know whether a person is good or bad.

How do children get AIDS?
If a woman who has the AIDS germ gets pregnant and has a baby, the baby might get the AIDS germ from her. This is how most children with AIDS have got it. Some children who were very sick with other illness were given special treatments called 'blood transfusions'. This means a little blood from another person is given to a sick person who needs it. If the AIDS germ was in the blood used for transfusions, the children who received the blood got AIDS.

What happens to children with AIDS?
Children with AIDS are a lot like other children with other illnesses and are quite often sick, but they will also feel better sometimes too.

What happens when you die?
Depending on the age and level of understanding of the child, you could use the following responses:

What do you think happens? (Elicit response from child.)

When a person dies, the things that made him or her alive stop happening. He or she doesn't breathe any more, and blood stops flowing in his or her body. He or she doesn't talk or laugh or cry or move. His or her life is over.

Don't make up things for children that you don't believe yourself. Don't tell children that dying is 'like going to sleep, except you never wake up'. This may create anxieties about death and about going to sleep.

This is an example of the way one parent described death to her seven-year-old:

'I believe when someone dies, the person's soul – an invisible part of him or her that feels feelings and cares for people – goes to a special place. Some people call this heaven, all the things that hurt someone during life no longer hurt. I think it's a nice place to be.'

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out and cleaning the body, to avoid contact with infected body fluids.

Considering the child

Make a child who is dying as comfortable as possible. This includes keeping them warm and dry, and providing pain relief if they seem to be in pain. Families should be encouraged to hug and touch the child and to involve them in family activities as much as possible – in very young children, non-verbal communication is very important.

Before the age of five it may be difficult to explain to a child that they are dying. But children often understand more than we think about what is going on. If a parent has died they may already be familiar with death. Children, like adults, may be sad, angry, afraid or anxious. Very young children may express anxiety through their behaviour, for example, suddenly being frightened of going to bed or being away from their mother.

It is important for children to have the opportunity to talk, to voice their feelings and fears. Just because they are silent does not mean they have no questions or are not worried.

If they ask questions, it is important to answer them simply and as honestly as possible. Adults may fear upsetting the child by telling the truth, but the child may be more scared and upset if he or she feels that secrets are being kept from him or her. If the child expresses fear about dying, focus on day to day plans and help him or her decide, if appropriate, who he or she wants to give special possessions to.

Planning for a child's future

Health and community workers can help parents who are sick or dying to plan for their children's future. What will happen to their children when they die is often parents' first concern. The decision about what happens to children may be taken by the father's family or the mother's family, depending on the culture.

Whoever takes the decision, planning ahead can relieve worry. Providing advice about legal, property and financial matters may be helpful. Where feasible, parents should make a legally binding will, to ensure that children inherit money or property, and that their wishes about who takes care of the children are made clear.

Practical issues to be considered include decisions about who will care for a child and guardianship, inheritance of land and property and decisions about schooling. Parents often want their children to stay together, and this is usually what the children themselves want too. As far as possible, depending on their age and family circumstances, children should be involved in decisions about their future and their wishes should be taken into account ■

Selected resources

Background material

AIDS and children: a lifetime of risk.
UNAIDS/PANOS, 1997.

Strategies for hope series. IALC.
A series of booklets which provide practical strategies on AIDS prevention and care in developing countries through an exploration of specific case studies.

- ***AIDS orphans: a community perspective from Tanzania.*** Mukoyogo, MC and Williams, G.
  ActionAid, 1991.
- ***Living positively with AIDS:*** The AIDS Support Organisation (TASO), Uganda. Hampton, J.
  ActionAid, 1990.
- ***The caring community: coping with AIDS in urban Uganda.*** Williams, G and Tamale, N.
  ActionAid, 1991.
- ***Meeting AIDS with compassion: AIDS care and prevention in Agomanya, Ghana.*** Hampton, J.
  ActionAid, 1991.

Children's rights and HIV: a framework for action.
National Children's Bureau.

Clinical tuberculosis. Crofton, J et al.
Macmillan, London, 1992.

Nutrition for developing countries. Savage King, F and Burgess, A.
ELBS, London, 1993.

Newsletters

AIDS Action.
Aimed at health workers and educators working at the primary level, it provides practical information on a wide range of care and prevention issues concerning AIDS, HIV and sexually transmitted infections. Published quarterly by AHRTAG. Free to developing countries.

Child Health Dialogue.
Aimed at a broad range of health workers in developing countries, it is a forum for the exchange of information about the prevention and treatment of key childhood diseases, as well as providing practical advice on related health education. Published quarterly by AHRTAG. Free to developing countries.

Practical guidelines and training materials

AIDS home care handbook. GPA/WHO (WHO/GPA/IDS/HCS/93.2). Geneva, 1993.

Child-to-child: a resource book. Bonati, G and Hawes, H.
Child-to-Child Trust. London, 1992.

Food for people living with HIV/AIDS.
Network of African People Living with HIV/AIDS. Nairobi.

Guidelines for the integrated management of childhood illness.
A series of workbooks forming the basis of a modular training course for health workers. WHO/UNICEF, 1996.

HIV testing and informed consent – guidelines for health care workers.
HIV and human rights pamphlet 2. AIDS Law Project, Witwatersrand, January 1995.

Practical guidelines for preventing infections transmitted by blood or air in health-care settings.
Discusses the risks to carers and patients of infections from hepatitis B, HIV and tuberculosis, and describes strategies to prevent infection. AHRTAG, 1996.

Tuberculosis and children: the missing diagnosis.
Explains how to diagnose and treat TB in children, and outlines control strategies. AHRTAG, 1996.

Organisations

AHRTAG
29-35 Farringdon Road, London EC1M 3JB, UK.
Tel: +44 171 242 0606; Fax:+44 171 242 0041

AIDS Law Project
University of Witwatersrand, P Bag 3, Witwatersrand 2050, South Africa.

Child-To-Child
Institute of Education, 20 Bedford Way, London WC1H 0AL, UK.
Tel: +44 171 612 6650; Fax: +44 171 612 6645

Children and AIDS International NGO Network (CAINN)
International Coalition on AIDS and Development, 100 Argyle Avenue, Ottawa, Ontario, K2P 1B4.

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Canada.
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Defence for Children International
PO Box 88, CH-1211 Geneva 20, Switzerland.

European Forum on HIV/AIDS
Children and Families, London Lighthouse,
111-117 Lancaster Road, London W11 1QT, UK.
Tel: +44 181 383 5697; Fax: +44 181 383 5620

Family AIDS Caring Trust
PO Box 970, Mutare, Zimbabwe.
Tel: +263 39 639 02

Family Health Trust
Anti-AIDS Project, PO RW 754, Lusaka, Zambia.
Tel: +260 1 223589; Fax: +260 1 222834

International Catholic Child Bureau (ICCB)
63 Rue de Lausanne, CH-1202, Geneva, Switzerland.
Tel: +41 22 731 3248; Fax: +41 22 731 7793

National Children's Bureau
8 Wakely Street, London EC1V 7QE, UK.
Tel: +44 171 278 9441; Fax: +44 171 278 9512

Network of African People Living with HIV/AIDS (NAP+)
PO Box 30218, Nairobi, Kenya.

Panos Institute/Panos Publications
9 White Lion Street, London N1 9PD, UK.
Tel: +44 171 278 1111; Fax: +44 171 278 0345

Teaching-aids At Low Cost (TALC)
PO Box 49, St Albans, Herts AL1 5TX, UK.
Tel: +44 1727 853869; Fax: +44 1727 846852

United Nations Children's Fund (UNICEF)
3 UN Plaza, New York, NY 10017, USA.
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UNAIDS
20 Avenue Appia, CH-1211 Geneva 27, Switzerland.
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WHO
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Glossary

Amniocentesis – taking a sample of the fluid surrounding the baby in the womb

Anaemia – reduced levels of haemoglobin – the substance inside red blood cells that carries oxygen

Bacteraemia – bacterial infection in the bloodstream

Caesarian section – an operation to remove the baby from the mother's abdomen

Colostrum – the milk produced by the mother in the first few days after birth

Counselling – aims to enable someone to cope better with stress, find realistic ways to solve problems and make informed decisions. Counselling is different from giving advice. Counselling is about enabling people to decide for themselves how to solve their problems. Giving advice is about suggesting how they might solve their problems. Counselling involves listening, learning, sharing and caring.

Cyanosis – blueness of the lips or tongue, most often due to a lack of oxygen

Hypoxia – lack of oxygen, indicated by symptoms such as restlessness, difficulty breathing (dyspnoea), inability to suck

Mother-to-child transmission (or vertical transmission) – refers to transmitting HIV during pregnancy, birth or breastfeeding

Prophylaxis (or preventive therapy) – chemoprophylaxis is the use of drugs to prevent disease

Sepsis – the presence of pus-forming bacteria in the blood or tissues, such as in septicaemia (blood poisoning)

Wet nursing – when someone other than the mother breastfeeds a baby

In this briefing paper, children can refer to anyone from 0 to 18 years of age. Young children refers to anyone from 0 to 5 years of age.

Appendix

Basic facts about HIV and AIDS

What is HIV?

HIV stands for **H**uman **I**mmunodeficiency **V**irus. The virus attacks the body's immune system, which protects against illness. The virus can only live inside a living human body. It only survives for a short time outside the body.

Once infected, an adult or a child is infected for life and there is currently no cure. But, children with HIV infection can remain healthy for several years, especially if they have access to good nutrition, treatment and care. Some children with HIV are still alive and well at the age of 15 or 16.

Other children with HIV may have periods of being well and periods of being ill. As HIV progresses and attacks the immune system the body is less able to fight off infection, and those infected suffer from HIV-related illnesses.

What is AIDS?

AIDS stands for **A**cquired **I**mmune **D**eficiency **S**yndrome. Acquired means to get. Immune means protected. Deficiency means a lack of. Syndrome means a group of different signs of a disease.

Adults and children with AIDS have serious illnesses and infections, usually after they have had HIV infection for some time and the virus has destroyed the immune system's ability to protect the body against disease.

How is HIV transmitted?

HIV is found in blood, semen, vaginal fluid and breastmilk. The virus can be transmitted through:

- Exchange of HIV-infected body fluids such as semen, vaginal fluid or blood during unprotected vaginal or anal sexual intercourse.
- HIV-infected blood transfusions or contaminated injecting equipment.
- Pregnancy, birth or breastfeeding, if the mother is infected with HIV.

How is HIV not transmitted?

- HIV is not transmitted through saliva, tears, vomit, faeces or urine, although small amounts of the virus have been found in these.
- HIV is not passed through unbroken skin, which forms an effective barrier.
- HIV is not spread through casual day to day contact such as touching someone with HIV or something they have used, sharing the same toilet seat or washing water.
- Nursing or caring for someone with HIV is not risky provided that sensible precautions are followed, such as disposing of sharp needles carefully and keeping cuts covered.
- HIV is not transmitted by mosquitoes.
- HIV is not transmitted to or from an infant or young child by cuddling, bathing, feeding or playing.

Appendix 2

Example of a workshop to explore issues around HIV/AIDS and young children

The following workshop outline and exercises may be helpful if you are planning to hold a workshop or are looking for ideas about methods to help health workers to think about HIV / AIDS and children.

Workshop outline

Day 1

SESSION 1

- ***Introduction and welcome***
- ***Workshop objectives***
- ***Introductions, expectations and fears***

Exercise 1: Introductions, expectations and fears

To help participants get to know one another, give each person a large piece of coloured card or plain paper. Ask each person to draw his or her own face, then to write down three expectations or fears he or she has about the workshop. When these are finished, pin them on the wall and ask participants to guess whose face belonged to whom, and ask each participant to introduce himself or herself.

SESSION 2

Setting the scene: HIV/AIDS and young children – what are the issues?

Exercise 2: Identifying issues of concern

Give each participant three blank cards (approximately 6x3 inches) and ask the participants to think about, and then write on the cards, what issues the words HIV / AIDS and young children raise for them. Collect the cards and ask the participants to cluster them into groups of similar or common issues. Display the cards on the wall, or lay them on the floor. Give each group of issues a title (for example, care and support issues, or counselling issues). Drawing out the issues and the process of grouping them can be a helpful way to start discussions and to plan how participants want to organise the workshop.

After grouping the cards, ask participants to indicate which area they are most interested in by making a pen mark on the relevant group.

SESSION 3

- ***Mother-to-child transmission***

This session can be used to provide participants with some background information, for example by watching a video, or listening to an outside speaker. Specific issues can then be discussed in more depth.

- ***Feedback and discussion***

Exercise 3: Mother-to-child transmission

Divide the participants into groups according to their main area of work: for example, home-based care workers, counsellors, clinicians. Each group could then discuss questions such as those listed below.

Questions for home-based care workers

Which women are more at risk of contracting HIV in pregnancy and why? In particular, what are the needs of HIV-positive women practising safer sex who want to conceive? How can vulnerable women who are pregnant be made aware of the need and be supported to practise safer sex? What potential community-based activities could be used to raise awareness of mother-to-child transmission?

Questions for counsellors
When is screening and testing of women for HIV / STDs during pregnancy appropriate? What are the advantages and disadvantages of testing? Identify and discuss any available guidelines for testing and counselling and their appropriateness.

Questions for clinicians
What are the key issues in providing good care for women during pregnancy and delivery in areas where HIV infection is common? In particular, what information and guidelines are currently available to health workers regarding care and management of pregnant women, good practice during delivery, care and management of newly delivered infants and mothers?

SESSION 4

- ***HIV/AIDS and breastfeeding***

Use short problem-posing case studies to highlight situations health workers and families may be faced with and draw out possible solutions.

Day 2

SESSION 1

Care and management of children with HIV infection and support to families

Again, participants can be divided into groups according to professional background or interest, to discuss issues and strategies related to, for example: clinical diagnosis, management and treatment, counselling, or care and support.

Exercise 4: Using role play to highlight problems

Groups of participants can use role play to present particularly difficult problems or scenarios to other participants. In the Zambia workshop, one group of participants presented a role play to illustrate the case of three young sisters aged under five whose parents had died and who were being abused by a male cousin. A relative took the girls to see a health worker, who treated them for STDs, then referred them to a counsellor. After an initial visit, the counsellor felt she could not continue until she had a discussion with the rest of the family. She was worried about sending the girls back to the home, even temporarily. The relative did not return. On enquiring, it became clear that the male cousin had been sent away and the girls sent to another village. The issue brought up was, how safe are the girls in their new home? What follow-up would they get, especially as they had been suffering from psychological as well as physical problems, and the elder child was very depressed?

Participants could be asked to discuss how they might deal with this situation.

SESSION 2

- *Young children affected by or vulnerable to HIV/AIDS*

Exercise 5: Communicating with the community

Participants are asked to develop role plays that can be used to start discussions in the community about children and HIV / AIDS, using a problem-posing approach. In the workshop in Zambia, a number of role plays were developed that prompted debate about child neglect and abuse, and the difficulties of families coping with HIV / AIDS.

Day 3

SESSION 1

Young children and HIV/AIDS: raising awareness

This session is intended to focus on ways health workers can raise awareness of HIV and young children and related issues. This includes thinking about:

- target groups in the community
- materials and methods that are available and that might be appropriate for the target audience.

It also gives participants the opportunity to share their experiences of working with different community members on HIV / AIDS awareness, and to consider how existing resources can be used and adapted.

SESSION 2

Ethical issues

Exercise 6: Exploring ethical issues

This practical exercise is intended to help participants explore some of the common ethical issues experienced by people caring for children with HIV and AIDS, and to help them to think about children's rights.

Mark a line on the ground, and mark one end YES and the other end NO. In between represents a continuum. Ask the group a series of questions. For each question, participants are asked to think about their response and to stand somewhere on the line depending on their response. The facilitator then asks two or three participants to explain why they chose to stand in a particular place. This highlights differing viewpoints and encourages active debate of the issues.

The following are examples of questions that could be asked:

- If the mother of a young child dies from HIV / AIDS and the grandmother takes over care, does she have the right to know the HIV status of the child?
- A three-year-old child is admitted to hospital with severe anaemia and signs of heart failure. The HIV testing kits for blood are finished. Would you give a transfusion of untested blood?
- Do parents hoping to adopt a child have the right to demand that the child they wish to adopt be tested for HIV?

SESSION 3

Taking things forward

Participants can be asked to think about improvements in practical management and care and support of pregnant women and young children.

Exercise 7: Action at different levels

Ask participants to consider what actions are needed at different levels and to suggest one practical and realistic action that could be taken at national, district, community and family level. Their responses are written on different coloured cards or paper and displayed on the wall. The suggestions can be used as a basis for discussion or action planning.

SESSION 4

Workshop evaluation

In addition to a short evaluation at the end of each day, it is useful to pull things together at the end through an evaluation of the overall workshop. This can be done by asking participants to:

- reflect on the main subjects and comment on what worked well, what the difficulties were, and how sessions could be improved in future
- respond to two questions – what has been the most useful aspect of the workshop for you personally – and – what are your suggestions for how it could have been improved
- rate whether or not the objectives and expectations (which can be displayed on a chart) have been met using a scoring system from 1 (not met) to 5 (fully met) ■

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Published as part of the World AIDS Campaign with support from

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